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Research (CHEER)

PRINCIPAL INVESTIGATOR: Lovell A. Jones

CONTRACTING ORGANIZATION:

The University of Texas MD Anderson Cancer Center

Houston, TX 77030

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Dorothy I. Height Center for Health Equity & Evaluation Research

INTRODUCTION

The project, entitled Dorothy I. Height Center for Health Equity & Evaluation Research is integrated into the overall structure of the CRMH. The study was a collaborative endeavor between the CRMH, MD Anderson's Department of Urology (Dr. Curtis Pettaway), Department of General Medicine (Dr. Robert J. Volk) and the Division of Cancer Prevention and Population Sciences. The funding has supported two interrelated, yet distinct efforts:

- A) To bridge the racial/ethnic gaps in patient care (including prevention, early detection, treatment and patient education), research and education/training in order to reduce disparities among racial/ethnic minorities and underserved populations, with continual input and participation from community residents and stakeholders.
- B) To develop and evaluate a Spanish language slide set for administration in group settings, adapted from the content of the current guidelines and existing, self-administered ACS early detection decision aid, to be made available to community-based educators and screening programs in support of an informed decision-making process for early detection of prostate cancer with Spanish-speaking men. A guide for educators will accompany the slide set so that materials may be distributed on a broad scale at the completion of the project.

Health disparities are well-documented, yet little progress has occurred in the last century toward narrowing the systemic, institutionalized and persistent differences in disease prevalence and outcomes for racial/ethnic minorities and other vulnerable populations, compared to non-minorities. In 1999, Congress provided funds for the creation of the Center for Research on Minority Health (CRMH), a comprehensive investigational, educational, and outreach unit of world-renowned The University of Texas M D Anderson Cancer Center (MD Anderson / UTMDACC) that focuses on cancer and other health issues disproportionately affecting racial/ethnic minorities and other medically-underserved populations. The CRMH uses the principles of community-based participatory research (CBPR) - which emphasize the equitable involvement of community members, representatives of community organizations, and diverse, multidisciplinary researchers in all aspects of the scientific process - to make effective, relevant, sustainable discoveries critical to reducing the burden of cancer among U.S. military personnel, its veterans and the U.S. population in general. Recently, the CRMH has transitioned into a newly formed Center for Health Equity & Evaluation Research (CHEER), a joint center between UTMDACC and The University of Houston.

Prompted by findings from large-scale screening trials in the US¹ and Europe,² the American Cancer Society (ACS) released an updated guideline on early detection of prostate cancer in 2010.³ The new guideline emphasizes the importance of men engaging in an informed decision-making process about the harms and potential benefits of prostate cancer screening before being tested. It further indicates that community-based screening events should not be continued unless a quality, informed decision-making process can be assured.³ Previously, our research team worked with the ACS to develop an English-language decision aid for use in community-based settings to promote informed decision making about prostate cancer screening. The aim of this project was to adapt the current decision aid "Testing for Prostate Cancer: Should I be tested? Is it the right choice for me?" for use with Spanish-speaking men in a community-based group setting. The final products are a 32-slide PowerPoint presentation

and an accompanying guide for educators that are linguistically and culturally appropriate for Spanish-speaking Hispanic men.

Figure 1. Original Aid

Figure 2. Adapted Aid





The overall infrastructure of the CRMH has been supported by Congressional Appropriations since 1999. Initially, those funds provided over 90% of the CRMH budget. Today, those funds constitute approximately 18% of the overall operational budget, primarily supporting the CRMH infrastructure.

Although this final report covers activities completed during the entire reporting period: September 30, 2011 to September 29, 2013. It should be noted that a no cost extension was granted for the period September 30, 2012 to September 29, 2013 with the primary purpose being the completion of the early detection prostate cancer patient decision aid for Spanish-speaking men pilot project.

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KEYWORDS

Prostate Cancer, Health Disparities, Cancer Screening, Informed Decision Making

BODY

A) The CRMH Infrastructure and its attendant patient care, research, educational, and community engagement activities: The major impact of the Congressional appropriations has been the funding of the infrastructure that has aided the CRMH in successfully establishing research, research training and education programs and community outreach efforts that create an environment conducive to accomplishing all of the specific aims of the original application.

Specific Aim 1: To maintain an infrastructure that supports a working network that develops culturally sensitive programs to support cancer awareness, cancer research, and training.

The model designed by the Center for Research on Minority Health (CRMH) (Appendix 1). emphasizes ongoing multi-directional interactions among all interested parties, creating a continuum of projects that reflect communication, trust, and scientific discovery based on the needs and priorities of both the community and the researchers, incorporating the principles of community-based research. These principles include: recognizing community as a unit of identity;

building on the strengths and resources within the community; facilitating collaborative partnerships in ALL phases of research; integrating knowledge and action for the mutual benefit of all partners; promoting co-learning and empowering practices that address social inequities; involving a cyclical process; addressing health from different cultural perspectives; and disseminating findings and knowledge gained to all partners.

Illustrated in Appendix 2 is the infrastructure of the CRMH. All of the CRMH cores work in unison and symbiotically to achieve the specific aims outlined in the original application. Funding provided by the appropriated funds supported much of the CRMH leadership: including Dr. Lovell A. Jones, CRMH Director; Dr. Richard Hajek, Research Core Director; Drs. Beverly Gor and Angel Tate

direct the Community Participatory Research and Outreach Core; Ms. Caren Blinka, Administrative Core Director and Clinical Core Director, and Mr. James Heggie, Research Education and Training Director; Dr. Yisheng Li, Shared Resources (Biostatistics and Data Management). Drs. Robert Volk and Curtis Pettaway leads the prostate cancer screening education guide and IDM efforts.

Specific Aim 2: To maintain a working network of community-based organizations; government agencies; research, educational, and medical institutions to address the disproportionate rates of cancer incidence and mortality in the Houston area through educational outreach, research, and procurement of needed services.

One of the key elements in the CRMH model is the development of a working network of key community-based organizations, government agencies, research, education and medical institutions. The key word in this is "working" and not just named. The CRMH has fostered numerous projects addressing health disparities, both directly and indirectly. For a more detailed description of some of these projects, visit the CRMH websites (www.mdanderson.org/crmh and www.healthdisparitiesresearch.org). As illustrated in

Appendix 1, all of the CRMH cores work together to maintain and further our networks that result in community, research, and educational projects to reduce health disparities. The following are examples of such working networks maintained and enhanced over the reporting time period.

Minority Health Coalitions

This group of health coalitions includes the Hispanic Health Coalition, African-American Health Coalition, Asian-American Health Coalition, of which CRMH staff members, specifically Community Relations staff members are active members or officers. Dr. Beverly Gor is one of the original founders of the Asian American Health Coalition. Dr. Torres and the CRMH Hispanic Community Relations Coordinator – Ms. Anedny Delgado-Laubscher worked closely with this coalition. The CRMH has played a pivotal role in revitalizing the Native American Health Coalition. This group, founded by Debra Scott, community advisory board member of the CRMH, was facilitated by Ms. Cheryl Downing, the former Native American community relations coordinator for the CRMH. All of these coalitions are excellent resources for community-based participatory research efforts.

The CRMH research has provided technical assistance and information to community-based organizations to successfully apply for their own funding. For example, the ASANA needs assessment provided evidence of the need for a community-based clinic in the Asian community and Dr. Beverly Gor, along with members of the Asian American Health Coalition successfully applied for funding to open the Hope Clinic and attain the status as FHQC look-alike. Similarly, the CRMH community Relations Core provided the Native American Health Coalition with support and

assistance to conduct research on colorectal cancer screening in the Native American community.

Networks for Research

Centers for Medicare and Medicaid Services (CMS): The CRMH successfully competed for one of six demonstration projects funded by CMS to investigate facilitated cancer screening services and patient navigation for Hispanic Medicare beneficiaries. This 4-year 5.4 million award was a tremendous effort towards addressing health disparities and health outcomes in this target population, essentially reducing systemic, cultural, educational, and logistical barriers that contribute to health disparities.

Establishing Comprehensive NCMHD Research Centers of Excellence - PEACE (Project Export, A Center of Excellence): Through this P60 Center project funded by the National Center on Minority Health & Health Disparities, the CRMH has established a center of excellence. The environmental health focus of this project incorporates gene-environment interaction studies and community-based needs assessments, thereby utilizing science to address environmental health issues facing communities of color and the medically underserved. The two primary research projects of this grant were: 1) Prevalence of Environmental and Genetic Risk Factors for Gastric Cancer in a Population of Mexican-American Children Residing in Texas. This project is led by Dr. Lovell Jones; 2) Neighborhood- and individual-level determinants of smoking cessation among Hispanics." This project is led by Dr. David Wetter, Chair of the Department of Health Disparities Research.

Latinos in a Network for Cancer Control (LINCC): There has been a major sub-contractual agreement and continued partnership between the CRMH and the University of Texas Health Science Center's LINCC project since its inception in 2002. This network was established through collaborations with the University of Texas School of Public Health, Center for Health Promotion and Prevention Research (a CDC-funded Prevention Research center), community-based organizations (National Center for Farmworker Health), health departments, practice settings, an NCI Community Network Program (Redes en Acción: The National Latino/Hispanic Cancer Network, Baylor College of Medicine) and the CRMH. LINCC is one of eight NIH-CDC funded CPCRNs across the nation funded through 2014. LINCC's mission is to reduce cancer-related health disparities among Latinos through a network of academic, public health, health service, and community partnerships engaged in community-based intervention, replication and dissemination research. This network has greatly facilitated the prostate cancer and IDM component of the project described below in Section II.

A Randomized Phase II Study of the Nutritional Supplements Juice Plus + and Juice Plus + Complete in Ovarian Cancer Patients: In this parallel group randomized trial, women were randomized to a low fat, high fiber condition or a low fat diet supplemented with fruit and vegetable concentrate capsules. The aims of the study were (1) examine the effectiveness of two dietary interventions on dietary intake, plasma biomarkers, and health related quality of life and (2) to determine whether differences exist between the intervention conditions on study outcomes. This project was funded by NSA International.

The SISTER Study: The CRMH was awarded a subcontract to increase minority recruitment into this large national cohort study funded by NIEHS investigating the environmental and genetic factors associated with breast cancer risk.

Susan G. Komen for the Cure (National): Drs. Chilton and Hajek successfully competed for a population sciences award of \$250,000 for three years to compare hormone levels and dietary habits of African American and West African women in Houston and West African women in

Nigeria. This work begins to address the environmental etiology of breast cancer in African American women.

Susan G. Komen for the Cure (Local): Drs. Chilton, Bevers, Hajek, and Gor successfully competed for an award of \$100,000 for one year to compare minority women who participated vs. minority women who chose not to participate in a previous large breast cancer chemoprevention clinical trial. The goal of this project is to increase inclusion of minority populations into STELLAR through community outreach and education using identified predictors of non- participation and of participation of minority women in clinical trials. There are myriad systemic, structural, and cultural barriers that may play a role in limiting minority women's access to and participation in clinical trials. An initial effort to understand barriers and facilitators to accrual and retention among women in Houston's minority communities, risk eligible women who did and did not participate in the previous breast cancer prevention clinical trial are interviewed regarding their perceptions. Systemic, structural, cultural and researcher-related barriers and facilitators are also assessed. This information was used to design, pilot, and test an intervention using The SISTER Study (NIEHS).

Katrina / Morehouse School of Medicine: Drs. Gor and Jones successfully competed for a subcontract award from Morehouse School of Medicine to assess the health issues of Asian Hurricane Katrina evacuees in Houston. As an extension of this project, the CRMH successfully negotiated securing resources for telemedicine and personal health information feasibility studies in the Houston area as well.

ExxonMobil Foundation: The ExxonMobil Foundation built upon their initial efforts targeting nutrition research in minority populations. The foundation announced a new commitment towards addressing minority health, health disparities, and education by committing \$100,000/yr for 5 years. These funds:

- Expanded successful efforts initiated by CRMH in Fort Bend ISD to Goose Creek Consolidated ISD
- Supported a minority graduate research assistant
- Facilitated HDEART Consortium projects
- Supported the training of area high school teachers to include environmental emphasis in the curriculum

Houston Endowment Inc.: The HEI awarded another development award (\$250,000) to continue to assist with the development of the HDEART Consortium.

Texas Higher Education Coordinating Board: The Education Core successfully competed for a 21 -month grant to investigate science centered inquiry-based educational activities in K-2 elementary classrooms. Although this may be deemed an educational achievement as well, it is considered educational research by the state. The Science Centered Inquiry-Based Educational Activities in Collaborating Elementary Classrooms (SCIENCE) Project is an environmental health science education partnership between the Fort Bend Independent School District (FBISD) and the CRMH that addresses the underrepresentation of African American and Hispanics in health professional and biomedical research careers. The purpose of the SCIENCE project is to develop the initial phase of a pipeline program aimed at providing an adequate scientific foundation that will enable minority students to progress through higher educational opportunities. The SCIENCE Project has advanced students' knowledge base in science resulting in positive change. Due to the overwhelming success of this project at the model school, the Fort Bend Independent School District has begun the process of implementing the program district-wide at all 26 elementary campuses where feasible. In addition, the sponsor requested and subsequently awarded a renewal proposal to expand and evaluate the effectiveness of the program in grades 3-4 at the model school.

The Role of Tumor-Associated Macrophages and Stress on Breast Cancer Prognosis in Pre- Menopausal African-American Women. The primary objective of this study was to investigate the role of immune cell infiltration and the influence of chronic stress on the immune system are required in order to elucidate the biological mechanisms underlying breast cancer progression, particularly in pre-menopausal African-American women. Specific aims are to: (1) delineate the relationship between immune cell density and the clinicopathologic characteristics of breast tumors of pre-menopausal African-American women and (2) investigate the relationship that chronic stress plays on immune cell function and the progression of breast cancer in pre-menopausal African-American women. This study was funded by the Kellogg Health Scholars Program.

Genomic Instability in Mexican-American Children Exposed to Environmental Toxins: An environmental and molecular epidemiology pilot study to explore if Mexican-American (MA) children living near agricultural fields where organophosphate pesticides (OP) have been applied and two superfund sites contaminated with organochlorine pesticides (OCP) and polychlorinated biphenyls (PCB) are at a higher risk for induced genetic instability (GI) than children of the same ethnicity and age living in the same region, but not near any Superfund sites or agricultural fields. In specific aim 1, we will determine OP urine levels from 25 children residing near the agricultural fields and compare these levels to those in 25 children living in the same region, but not near the agricultural fields. In specific aim 2, we will determine PCB serum levels from 25 children living near the Donna Superfund site and compare these levels to those in 25 children living in the same region, but not near the Donna Superfund site. In specific aim 3, we will determine OCP serum levels from 25 children living near the Mission Superfund site and compare these levels to those in 25 children from the same region, not living near the Mission Superfund site. This will determine the relationship between OP, OCP and PCB exposure and residential status. This study was funded by the Center for Research on Environmental Diseases.

Health and Cancer Issues in the South Asian Community: The overall objectives of this study are to assess the unmet health and cancer needs of the South Asian population in the Greater Houston area and to determine barriers and other factors that affect health in this population, so that we can address these issues by partnering with other researchers, public health and community organizations. Major emphasis will be placed on cancer, heart disease, diabetes, and other relevant health concerns, such as the use of complementary and alternative therapies. This study was funded by discretionary funded provided by UTMDACC

The Circle of Sisters: is a breast cancer education and outreach initiative for American Indian women. This project builds on our previous initiatives in the American Indian community, including facilitating meetings of the Native American Health Coalition, coordinating an annual Native American Health Summit and colorectal cancer education programs in the Native American communities and a Circle of Sisters event for Native American women planned for May of this year in which we will pilot test many of the proposed activities. The long term goal of the project is to improve breast cancer screening rates by increasing awareness of the importance of early detection and screening, cancer risk reduction through nutrition and physical activity, and education about breast cancer screening and support resources. The program will include a full day of culturally tailored educational and leisure activities focused on American Indian women living on and off the Alabama-Coushatta reservation, especially those with financial, educational or transportation barriers to mammography screening. This project was funded by the NCI and the Mayo Clinic.

Houston Breast Cancer Task Force (Avon Foundation): The breast cancer mortality disparity data released February 5, 2008 at the Avon Breast Cancer Forum has galvanized a citywide effort, the Houston Breast Cancer Task Force, to better understand breast health disparities and to develop solutions to the problem. The mortality disparity is only one component and more thorough studies of current disparities in breast health for the women of Houston are warranted. The task force is currently working to identify the capacity of

screening and diagnostic treatment facilities in the Houston community. This study was funded by the AVON Foundation.

CAN DO Houston: CAN DO Houston is a holistic community-based initiative that aims to prevent and diminish childhood obesity in Houston and surrounding communities. CAN DO Houston LISTENS to the needs of the community and addresses physical activity, nutrition, and healthy minds in the community, school, after-school, home, and work environments based on the needs of the community. The program utilizes existing resources and evidence-based practices and addresses gaps in services by enabling the broadest collaboration of individuals, institutions, and organizations. CAN DO Houston is a combined effort of the Mayor's Wellness Council, Houston Wellness Association, and many community partners. This study was funded by In kind donations from M.D. Anderson CRMH, Coca-Cola North American/Minute Maid, City of Houston Department of Parks and Recreation, Department, and Robert Wood Johnson Foundation.

Networks for Educational Outreach and Training

Health Disparities Education, Awareness, Research, & Training (HDEART) Consortium: One of the most important achievements was the formation of HDEART in September of 2003. An institution can become a part of HDEART via a letter of agreement from the President and/or CEO agreeing to participate in HDEART activities to address health disparities, not just limited to educational activities. Therefore, it is an agreement at the highest level. The

purpose of the HDEART Consortium is to share resources to develop academic research and educational program related to health disparities. The first effort developed a course(s) which would be combined with existing courses to create an academic specialty (either through certification or an academic minor) in health disparities. The HDEART currently has 38 members, whose names and affiliations are provided in Appendix 3.

Center Health Disparities Curriculum and Anchor Course: Although the anchor course was first offered at the University of Houston in the Fall 2002, it formally became a HDEART course when offered on the Rice University campus in the Fall 2003. Since then, it has been offered and rotated on the following campuses: Texas Southern University, The University of Houston-Downtown, Rice University, The University of Houston, and The University of Texas Health Science Center-Houston's School of Public Health. All CRMH faculty participate in the teaching of this course. The course was offered last Fall at the University of Houston Downtown (Appendix 4) with 93 students (89 undergraduate / 4 graduate). The course will be offered at the Texas Southern University this Fall (2012; Appendix 5, with additional teleconferencing sites this year.

Health Disparities Workshop: This summer week-long workshop is a concentrated version of the Anchor Course described above for students, staff, faculty, and community members nationwide. Over the past six years beginning in June 2003 through June 2012, we have had over 2,800 participants per year attend the annual summer workshops consisting of social workers, undergraduate and graduate students from HDEART

Consortium member campuses, postdoctoral fellows, Kellogg Scholars, social workers, physicians, nurses, and other health care professionals.

The 10th Annual Health Disparities Summer Workshop was held in conjunction with the 25th Anniversary of the Biennial Symposium Series June 26 – July 1, 2012 at Hilton Americas, Houston.

25th Anniversary of the Biennial Symposium on Minorities, the Medically Underserved & Health Equity: Empowering Communities in the Era of Health Care Reform: The Symposia were initially sponsored by the University of Texas M.D. Anderson Cancer Center, the Chronic Disease Prevention and Control Research Center (CDRC) at Baylor College of Medicine and the Intercultural Cancer Council (ICC). The 25th Anniversary Symposium was a reorganized and restructured continuation of a 22-year series of biennial symposia and semiannual Educational Forum meetings that address the unequal burden of cancer among racial/ethnic minorities and other medically underserved groups. The broad scope of this Symposium and the upcoming ones are concerned with science updates on prevention, screening, treatment, survivorship and caregiver issues; cancer data and surveillance; research and clinical trials; quality of life, pain and palliative care, end-of-life and hospice care; advocacy training, behavioral science, cultural competence and health disparities; training in writing grant proposals for communitybased organizations (CBOs), health communication; healthy lifestyles; information technology, patient and public education, patient navigation; population science; spirituality and health; and tobacco prevention, cessation, and advocacy. (Appendix 6)

National Minority Cancer Awareness Week Luncheon: Over the past 12 years the CRMH has observed National Minority Cancer Awareness Week and the Biennial Symposium Series on "Minorities, the Medically Underserved & Cancer" with a symposium luncheon hosted during the third full week of April. The National Minority Cancer Awareness Week Luncheon (NMCAWL) hosts approximately 300 health care professionals, elected officials and community members each year. The luncheon honors individuals, communitybased organizations and scientists that have made significant contributions to eliminating health disparities in the area of cancer outreach and education. In 2007, the CRMH observed the 20th Annual National Minority Cancer Awareness Week and Biennial Symposium Series on "Minorities, the Medically Underserved & Cancer". The keynote speakers were former surgeon generals, Joycelyn Elders, M.D. (1993-1994), and David L. Satcher, M.D., Ph.D. (1998-2001), In 2008 the symposium's keynote was former Department of State Health Services Commissioner Eduardo J. Sanchez, M.D., M.P.H. The University of Houston President and University of Houston System Chancellor Dr. Renu Khator, PhD was the 2009 keynote with the Executive Vice Chancellor for Health Affairs of the The University of Texas System and former president of the IOM, Dr. Kenneth Shine taking this role in 2011. The 2010 keynote was HEB's CEO Scott McClelland, MBA. The 2012 keynote was Jay Moskowitz, PhD, the President and CEO of Health Sciences South Carolina.

In 1986, Lovell Jones, Ph.D., approached Senator Lloyd Bentsen and Representative Mervyn Dymally to support a joint resolution to designate the third week in April as National Minority Cancer Awareness Week. On April 8, 1987, the U. S. House of Representatives Joint Resolution 119 designated the third week in April as "National

Minority Cancer Awareness Week." The American Medical Association and the American Cancer Society both endorsed the resolution as a means of drawing attention to the problem among minorities and the poor (Appendix 7).

Implementation of the Bioethics Initiative for Equity in Health Care and Research: The first aim of the initiative is to develop an institutionally linked but free-standing program dedicated to the training of racial and ethnic minorities in bioethics to address the underrepresentation of minorities in clinical trials. Toward that aim, researchers within MD Anderson Cancer Center's Department of Health Disparities Research and the Center for Research on Minority Health partnered with researchers in the Section of Integrated Ethics in the Department of Critical Care. Created to support the endeavor was an advisory board, the Multidisciplinary Advisory Committee, composed of internal and external community members committed to the project's goals. Members, who represent the ethnically and racially diverse Houston metropolitan area, come from within MD Anderson and from Houston's larger community, and include men and women who are oncologists and others who have been cancer patients and cancer family caregivers. Other principal players who are integral to the program are mentors who work with the postdoctoral fellows and interns. These have included initiative staff, a physician/researcher who was recently a Robert Wood Johnson policy fellow, and the director of MD Anderson Cancer Center's Minority and Women Clinical Trials Recruitment Program. The second aim of the initiative is to increase the number of women and underrepresented ethnic and racial minority members in the bioethics academic enterprise. Seven of nine participants have been from minority racial groups, but all have been women. Interns have undertaken clinical ethics coursework, and the clinical observation in the company of Integrated Ethics faculty allows them to see in practice some of the issues explored in class readings and lectures. Other activities intended to equip them for participation in the bioethics academic enterprise includes attending the Disparities in Health in America Workshop, sponsored annually at MD Anderson Cancer Center by the Center for Research on Minority Health; undergoing other training, including human subjects protection training and communications training. The third aim is to develop and use nontraditional methods to build trust in the health care system to bolster minority participation in clinical trials. The initiative has sought to build trust in the health care system, in part, by creating leaders in bioethics thought through the internships and fellowships, but it has also sought to engage the community in discussions around minority representation in clinical trials by hosting three educational sessions (webinars) on the issues of responsible conduct of research, the Havasupai settlement, and distrust of clinical trials by minority populations. Posting a Web site about the initiative on the MD Anderson Cancer Center's site (www.mdanderson.org) provides another venue. More traditional methods of disseminating research findings used by the project include submission of a manuscript about the ethics of limiting a pregnant woman's participation in clinical trials to the Journal of Medical Ethics. An article on ethics practiced in a medical center during a hurricane has also been accepted. This study was funded by the NIH.

Kellogg Scholars in Health Disparities: The CRMH was a training site for Kellogg Scholars in Health Disparities. Dr. King (Pilot 1) and Dr. Teal (Assistant Professor, Houston Center for Quality of Care & Utilization Studies, Veterans Affairs Medical Center and Baylor College of Medicine) completed their tenure as the first scholars in the CRMH in 2006. Additional scholars through 2013 have included Dr. Angelica Herrera (Assistant Professor, University of Maryland Baltimore County), Dr. Gina Evans (Assistant Professor, Baylor College of Medicine) and Dr. Shedra Amy Snipes

(Assistant Professor, The Pennsylvannia State University) who finished in 2008-09. Drs. Anthony Omojasola (COO, Park DuValle Community Health Center) and Patricia Miranda (Assistant Professor, The Pennsylvania State University) both finished in 2011. Dr. Lucinda Nevarez has accepted an assistant professor position at the University of Texas Health Science Center – San Antonio. Dr. Shelly Hovick accepted an assistant professor position at Ohio State University, Kimberly Enard accepted an assistant professor position at St. Louis University, and Stacy Lloyd accepted a fellowship at Baylor College of Medicine.

PVAMU Nursing Model: In the Fall 2005 semester, as part of Project EXPORT, new environmental health content was added to the nursing curricula to increase the number of PVAMU minority nurse researchers in the area of environmental health. Implementation began in the fall of 2006 and continues to the present.

M.D. Anderson Guest Lecturers: The CRMH continued to sponsor lecturers who were leaders in the Health Disparities field on a regular basis.

Cancer Network: The CRMH worked with the community-based Cancer Network for the Houston area. Network members include community leaders and non-profit organizations that advise the CRMH on ways to best address health disparities in cancer detection and treatment and facilitate the sharing of information, resources, and ideas.

Website: Along with the Department of Health Disparities Research, a featured site has been developed directly off of the main M. D. Anderson website http://www.mdanderson.org/topics under "Race, Ethnicity, and Cancer". The Center websites www.mdanderson.org/crmh and www.healthdisparitiesresearch.org continued to serve as an information resource regarding minority health, providing Internet links to related websites and a calendar of community events and activities related to cancer awareness, prevention, and education.

Texas Health Disparities Task Force: Dr. Beverly Gor serves as a member of the Texas Health Disparities Task Force that was created by the legislature to help eliminate inequities in health care and access to health care across the state. The CRMH serves as a resource for Dr. Gor as she fulfills her responsibilities on the Task Force.

UNC Videoconference: The CRMH hosted the five-day Summer Public Health Research Videoconference on Minority Health produced by the University of North Carolina at Chappell Hill School of Public Health in June 2004-2012 targeting academic and community members appropriate to each day's topic.

Networks for Procurement of Needed Services:

The Prostate Outreach Project (POP) Mobil Unit: MD Anderson's POP was a community-based education and early prostate cancer detection program initially established in two underserved primarily African American communities in June 2003. Community sites were selected to recruit African American men that were more likely to be indigent and could most benefit from program services. The program was sponsored

via Congressional appropriations, as well as funds administered via The University Cancer Foundation of M. D. Anderson, the Prostate Cancer Research Program and the Division of Cancer Prevention and Population Sciences. Dr. Curtis Pettaway of the Department of Urology serves as the program director. The goal was to impact prostate cancer mortality among underserved African Americans.

Texas Department of Health: The CRMH was working with State Cancer Registry to further explore the integrity and validation of data on certain minority populations within the State. Several analyses have been initiated, and preliminary results showed a significant underreporting of cancer incidence among certain minority subgroups including Native Americans.

HOPE Clinic: As noted above, the Asian American Health Coalition (AAHC) operates this community health center which serves a large percentage of the medically underserved Asian Americans in Southwest Houston. The HOPE clinic addresses the needs identified in the Asian American Health Needs Assessment survey such as referrals to cancer screening services. To address this issue, the AAHC and the CRMH have applied for and obtained two grants from the Texas Cancer Council to increase cancer screening. The AAHC has also received funding from W.K. Kellogg Foundation (the Health through Action Partnership Grant) to reduce disparities in these populations. The HOPE Clinic is now a recognized Federal Qualified Health Center.

Gateway to Care: the CRMH was a member of this community access collaborative, comprised of over 170 public and private safety net health systems, coalitions, advocacy groups and social service providers working together to assist the approximately 1.09 million uninsured and the additional 500,000 underinsured residents in the Greater Houston Area in receiving medical care at the most appropriate setting. Its major initiatives include the Provider Health Network, Medical Reserve Corps, Federally Qualified Health Centers as well as many other important programs. Gateway to Care also conducts navigation training and has participated in the training of CRMH patient navigators and community health workers.

Harris County Public Health Care System Council: Dr. Beverly Gor was appointed to this 21 member advisory board which seeks to develop and maintain a comprehensive, coordinated, and evolving health care delivery system to provide necessary population-based public health interventions and access to a network of preventive and primary care services with particular emphasis on care for persons with little or no medical insurance.

The Circle of Sisters: is a breast cancer education and outreach initiative for American Indian women. This project builds on our previous initiatives in the American Indian community, including facilitating meetings of the Native American Health Coalition, coordinating an annual Native American Health Summit and colorectal cancer education programs in the Native American communities and a Circle of Sisters event for Native American women planned for May of this year in which we will pilot test many of the proposed activities. The long term goal of the project is to improve breast cancer screening rates by increasing awareness of the importance of early detection and screening, cancer risk reduction through nutrition and physical activity, and education about breast cancer screening and support resources. The program will include a full day of culturally tailored educational and leisure activities focused on American Indian women

living on and off the Alabama-Coushatta reservation, especially those with financial, educational or transportation barriers to mammography screening. This project was funded by the NCI and the Mayo Clinic as well as the Pink Ribbon Project.

Boat People SOS: During the Hurricanes Katrina/Rita crisis, Dr. Gor and Truong Son Hoang assisted Asian evacuees with facilitating medical services or completing FEMA applications. This project helped to identify the major health needs of this population and the partnering with Asian Pacific American and other community-based organizations to design culturally and linguistically appropriate programs and interventions. Through the CRMH relationship with Morehouse School of Medicine, additional resources such as access to telepsychiatry services and the provision of electronic medical records were also facilitated to Katrina evacuees.

Houston Breast Cancer Task Force (Avon Foundation): The breast cancer mortality disparity data released February 5, 2008 at the Avon Breast Cancer Forum has galvanized a citywide effort, the Houston Breast Cancer Task Force, to better understand breast health disparities and to develop solutions to the problem. The mortality disparity is only one component and more thorough studies of current disparities in breast health for the women of Houston are warranted. The next step of the task force is to identify the capacity of screening and diagnostic treatment facilities in the Houston community. This study was funded by the AVON Foundation.

Specific Aim 3: To conduct needs assessments to determine the distinct cultural traditions, behaviors and perceptions that shape the health attitudes of our target groups; and to determine ways to promote health education in these communities. This process was continual to ensure that the program is responsive to the target populations.

Asian American Health Needs Assessment (AsANA): Researchers from the CRMH have completed the first phase of the Asian American Health Needs Assessment project by conducting the first-ever comprehensive telephone survey to assess the health issues of Chinese and Vietnamese populations in Houston and surrounding areas. The survey was conducted in Vietnamese, Cantonese, Mandarin and English. Of the 1,808 randomly selected Chinese and Vietnamese contacted, 814 individuals (402 Chinese, 412 Vietnamese) completed the survey. CRMH researchers are analyzing the data from the study to understand and describe the health needs, risks and practices of these populations. The large data set has provided both quantitative and qualitative health information about these two Asian communities. A community report highlighting the most common health risk factors for Chinese and Vietnamese in Houston has recently been released: (http://www.mdanderson.org/pdf/health_disparities_asana_cr_final.pdf) and widely disseminated in the two communities and research community: e.g., APHA (http://www.mdanderson.org/pdf/apha_poster.pdf); ICC

(http://www.mdanderson.org/pdf/iccposter.pdf); Texas Public Health Association (http://www.mdanderson.org/pdf/healthy_people_2010.pdf) and Community outreach and media campaign of the AsANA study

(http://www.mdanderson.org/pdf/media_outreach_icc_presentation.pdf). Results of the survey have helped identify pressing health risks and needs and have provided the data needed for designing culturally-appropriate health programs in this community.

The <u>Fresno Environmental Survey of Needs and Opinions (FRESNO)</u> project was an environmental health pilot study conducted by the CRMH to assess the Fresno, Texas

community's perceptions of environmental exposure and associated health concerns. A secondary objective of the study was to collect data on the perceptions of genetic testing and participating in research studies among African-American and Hispanic Fresno, Texas residents. A community advisory board was established to develop and implement the study. Key informant interviews and focus group sessions were conducted, and the information collected was used to educate the community on environmental exposures, health concerns, and residential needs specifically related to Fresno, Texas. Findings from this needs assessment have been published and disseminated during the reporting period.

The HHS Hispanics Elders Project "Improving Hispanic Elders' Health: Community Partnerships for Evidence-Based Solutions" is year-long pilot project intended to bring together local leaders from Houston and seven other metropolitan area communities with the primary objective of combating health disparities in the growing population of Hispanic elderly. Five federal agencies - Administration on Aging (AoA), the Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention (CDC), the Centers for Medicare and Medicaid Services (CMS), and the Health Resources and Services Administration (HRSA), all part of the United States Department of Health and Human Services (DHHS) - coordinate this initiative through AcademyHealth. The eight participating cities include: Chicago, IL; McAllen, Miami, New York, San Antonio, and San Diego and Los Angeles, CA. This spring, Houston's team - Neighborhood Centers, Inc., the Area Agency on Aging, Denver Harbor Clinic, St Lukes Episcopal Charities, Gateway to Care, IntraCare Hospitals, and MD Anderson (CRMH)- completed a 15-minute key informant online survey to help prioritize health disparity areas and target community sites to launch a community-based intervention. Findings from the survey helped define key focus areas such as the development of a diabetes intervention for Hispanic elderly in the Houston area.

The Environmental Community Assessment Project (E-CAP): Galena Park is a community assessment and planning initiative that is conducted by Harris County Public Health and Environmental Services (HCPHES). The CRMH served as a consultant on the project by providing recommendations on how best to conduct a culturally competent environmental health assessment in a minority community. The goal of E-CAP Galena Park is to engage a Harris County community in a comprehensive community assessment and dialogue processes to determine the extent of inequities in environmental conditions and resulting health disparities. In addition, E-CAP Galena Park aims to effect change through community mobilization, capacity development, and advocacy for policy solutions to address environmental conditions that impact health. The Protocol for Assessing Community Excellence in Environmental Health (PACE-EH) methodology, developed by the National Association for City and County Health Officials, will be used to facilitate the community dialogue process. PACE-EH is designed to help communities systematically conduct and act on an assessment of environmental health status in their community. Key project activities conducted during E-CAP Galena Park include: reviewing and analyzing existing health and environmental data sources; identifying and mapping environmental factors that potentially impact health in a Harris County community; and facilitating the community dialogue process. Community interface with human subjects will occur through a series of activities that may include focus groups, surveys, town hall meetings, and key

informant interviews conducted with community- invested and residential participants. Community members and local public health professionals will also be involved in the developed PACE-EH community-based environmental health assessment team, which will be primarily responsible for completing the community assessment process.

Texas Partnership to Address and Eliminate Health Disparities (TPAHD): The Center for Research on Minority Health at the University of Texas M.D. Anderson Cancer Center had a contract with the Health and Human Services Commission to provide an assessment for the Texas State Partnership to Address and Eliminate Health Disparities (TPAHD) project. The primary goal of TPAHD was to maintain a collaborative, in preparation for developing statewide health disparities initiatives. It was the role of MD Anderson to: 1) provide an assessment of the process; 2) to determine the effectiveness of proposed interventions/policies; and 3) to estimate the impact on health disparities in Texas. This study was funded by the State of Texas Office for the Elimination of Health Disparities.

Task Force on Halting the Increase in Overweight and Obesity in Houston/Harris County Children: Dr. Lovell Jones is a key member of this groundbreaking, Mayor of Houston led taskforce that is developing a comprehensive strategy to halt the increase in overweight and obesity among children in Houston/Harris County. The task force is examining the obvious and recommended actions to halt the obesity epidemic such as neighborhoods safe for unstructured play, eating habits of parents and custodial adults, cultural food preparation practices, accessibility to full service food retail outlets, etc. The task force is obtaining information from local researchers and professionals who have been working in the area of nutrition, food security, physical activity, and childhood obesity. It is also obtaining input from neighborhood associations, parent groups, youth sports associations, economic development organizations, and others that influence the overall context of Houston's neighborhoods. The task force will synthesize the information with recommendations for action, responsible parties, timelines, and resources to address the problems of childhood obesity in a strategic collaboration that can be shared with the community-at-large, and measured for changes and progress. The task force presented a final report to Houston City Council, Harris County Commissioners Court, and the general public.

Caregiver Assessments of the Quality of Home Hospice Care: A Comparison Across 3 Ethnic Groups: The study involves a 35-minute cross-sectional phone interview with 128 bereaved caregivers who have completed their participation in the parent study and have lost their loved ones (hospice patients) within 3-23 months. The primary purpose is to investigate the associations between the caregivers' quality of hospice care assessments and ethnicity, parenteral hydration status of the patient, and levels of grief of the bereaved caregivers. The aims of the study are to administer the Family Evaluation of Hospice Care (FEHC) to caregivers already recruited into the parent grant and conduct supplemental analyses to investigate the associations between the quality of hospice care ratings and: a) the parenteral hydration status of the patient; b) ethnicity; c) past and current levels of grief. This study was funded by the National Cancer Institute.

The Health and Information Seeking Behaviors of the Southern Poor: The goal of this project is to understand how low-income audiences in the South perceive a wide range of health risks, how much they worry about and feel susceptible to these multiple health risks, and the degree to which they seek and process health information. Focus groups and

interviews were held in three southern with White and African Americans. A random digit dial phone survey was also conducted to find out more about why low-income people respond to some health risks and not others. Specific aims are to (1) better understand how low-income people perceive multiple health risks and cope with them on limited resources; (2) Assess worry across ten unique health risks and differences in worry by race, gender, age, and educational level. From risks considered to be of the most worry, we also assessed how worry and perceived risk impacts decisions to engage in health protective actions; (3) Test the assumption that increased perception of risk will trigger an emotional response, worry, that in turn triggers an assessment of health information needs and subsequently information seeking and processing. This study was funded by the Centers for Disease Control and Prevention as Center of Excellence in Health

CAN DO Houston: CAN DO Houston is a holistic community-based initiative that aims to prevent and diminish childhood obesity in Houston and surrounding communities. CAN DO Houston LISTENS to the needs of the community and addresses physical activity, nutrition, and healthy minds in the community, school, after-school, home, and work environments based on the needs of the community. The program utilizes existing resources and evidence-based practices and addresses gaps in services by enabling the broadest collaboration of individuals, institutions, and organizations. CAN DO Houston is a combined effort of the Mayor's Wellness Council, Houston Wellness Association, and many community partners. This study was funded by In kind donations from MD Anderson CRMH, Coca-Cola North American/Minute Maid, City of Houston Department of Parks and Recreation, Department, and Robert Wood Johnson Foundation.

Discount Generic Prescription Utilization in Low-income Populations: The primary objective of this study was to identify the factors associated with awareness and utilization of generic prescription drug discount programs in low-income populations in Houston. The specific aims were to (1) conduct a survey to determine the relationship between awareness of the discount generic prescription program and utilization of the program and (2) conduct focus groups to determine awareness, beliefs, and utilization of the discount generic prescription program among low-income populations in Houston.

Perceptions of cervical cancer among Asian Americans: The purpose of these focus groups was to increase our understanding of these communities' perceptions of cervical cancer, cervical cancer screening and HPV so that educational resources and programs can be developed for these populations on the risks of cervical cancer and approaches to decreasing their risks. This study was funded by the Asian American Health Coalition.

Health and Cancer Issues in the South Asian Community: The overall objectives of this study were to assess the unmet health and cancer needs of the South Asian population in the Greater Houston area and to determine barriers and other factors that affect health in this population, so that we can address these issues by partnering with other researchers, public health and community organizations. Major emphasis will be placed on cancer, heart disease, diabetes, and other relevant health concerns, such as the use of complementary and alternative therapies. This study was funded by discretionary funded provided by MD Anderson.

Specific Aim 4: To provide mentors and extensive training programs to support minority students pursuing careers in biomedical, epidemiological, and behavioral, and health services research.

The goal of the CRMH's Educational Core was to increase the number of individuals in health disparities research by creating unique educational programs and linking these to already existing programs. As noted above, the CRMH has established a consortium of academic and health institutions (the Health Disparities Education, Awareness, Research & Training [HDEART] Consortium). One of its goals is to create an academic degree/certificate granting program in health disparities. The CRMH/HDEART sponsors several educational activities including the UNC Videoconference, the National Minority Cancer Awareness Week Luncheon, the Annual Summer Workshop on Health Disparities and the anchor health disparities course entitled "Disparities in Health in America: Working Toward Social Justice." Another training course that addresses health disparities and targeting mostly minority students is "Topics in Genomics" which is co-sponsored each year with Prairie View A&M Universit. In addition, CRMH/HDEART is creating a pipeline program which will take students from kindergarten to postgraduate education. This program is part of the EXPORT grant recently awarded to the CRMH.

The following section provides a detailed description of four of the CRMH's most prominent programs that support minority students pursuing careers in biomedical, epidemiological, and behavioral research.

- 1) Export Project: The CRMH was awarded its original P60 Center Grant in 2003 to establish a Center of Excellence in Partnerships for Community Outreach Research on Health Disparities and Training (Project EXPORT). In 2007, the CRMH successfully competed for the renewal of Project EXPORT, known as Project EXPORT A Center of Excellence (PEACE). One of the projects included was the PIPELINE Scientific Training Program (PSTP) Linking Training from High School to Graduate Programs, which was implemented by the CRMH Education Core. The PSTP, linked with the SCIENCE Project, introduces interested and qualified Texas young people to a research environment, utilizing an elementary setting. It also provides firsthand experience in the varied career opportunities available in the biomedical sciences, public health and community- based participatory research for young people. The eight-week program for high school and college students generally runs from early June through the last week of July and selects two to three students high school students, along with one or more undergraduates, to participate.
- 2) SCIENCE Project: Science Centered Inquiry-Based Educational Activities in Collaborating Elementary Classrooms (SCIENCE) Project. The overall goal of SCIENCE Project was to reduce the under-representation of African American and Hispanics in health professional and biomedical research careers. Specific aims are to (1) increase the quality of environmental health science teaching and learning through professional development at the Environmental Health Science Summer Institute (EHS-SI) for primary Burton Elementary School teachers; (2) increase inquiry-based science activities among African-American and Hispanic kindergarten through 2nd grade students; and (3) enhance inquiry-based science activities among African-American and Hispanic

kindergarten through 5th grade students attending Burton Elementary School by developing and implementing an evidence-based level appropriate science education roadmap. This project was funded by the Texas Higher Education Coordinating Board.

- 3) Implementation of the Bioethics Initiative for Equity in Health Care and Research: The first aim of the initiative was to develop an institutionally linked but free-standing program dedicated to the training of racial and ethnic minorities in bioethics to address the underrepresentation of minorities in clinical trials. Toward that aim, researchers within MD Anderson's Department of Health Disparities Research and the Center for Research on Minority Health partnered with researchers in the Section of Integrated Ethics in the Department of Critical Care. Created to support the endeavor was an advisory board, the Multidisciplinary Advisory Committee, composed of internal and external community members committed to the project's goals. Members, who represent the ethnically and racially diverse Houston metropolitan area, come from within MD Anderson and from Houston's larger community, and include men and women who are oncologists and others who have been cancer patients and cancer family caregivers. Other principal players who are integral to the program are mentors who work with the postdoctoral fellows and interns. These have included initiative staff, a physician/researcher who was recently a Robert Wood Johnson policy fellow, and the director of MD Anderson Cancer Center's Minority and Women Clinical Trials Recruitment Program. The second aim of the initiative is to increase the number of women and underrepresented ethnic and racial minority members in the bioethics academic enterprise. Seven of nine participants have been from minority racial groups, but all have been women. Interns have undertaken clinical ethics coursework, and the clinical observation in the company of Integrated Ethics faculty allows them to see in practice some of the issues explored in class readings and lectures. Other activities intended to equip them for participation in the bioethics academic enterprise includes attending the Disparities in Health in America Workshop, sponsored annually at MD Anderson Cancer Center by the Center for Research on Minority Health; undergoing other training, including human subjects protection training and communications training. The third aim is to develop and use nontraditional methods to build trust in the health care system to bolster minority participation in clinical trials. The initiative has sought to build trust in the health care system, in part, by creating leaders in bioethics thought through the internships and fellowships, but it has also sought to engage the community in discussions around minority representation in clinical trials by hosting three educational sessions (webinars) on the issues of responsible conduct of research, the Havasupai settlement, and distrust of clinical trials by minority populations. Posting a Web site about the initiative on the MD Anderson Cancer Center's site (www.mdanderson.org) provides another venue. More traditional methods of disseminating research findings used by the project include submission of a manuscript about the ethics of limiting a pregnant woman's participation in clinical trials to the Journal of Medical Ethics. An article on ethics practiced in a medical center during a hurricane has also been accepted. This study was funded by the NIH.
- 4) The Kellogg Health Scholars Program: The CRMH/ HDEART Consortium was one of four training sites in the multidisciplinary-disparities tract in the U.S. Our site focused primarily on using a biopsyshosocial approach in health disparities. Dr. Lovell Jones is the Site Director for the CRMH/HDEART site. The CRMH/HDEART brings together the strengths of its 28 member institutions to focus on developing solutions to ameliorate health

disparities. (See Appendix 3). The program is comprised of two tracks: a) A multidisciplinary-disparities track whose intent is to prepare a new generation of minority scientists for careers and leadership roles in health disparities and health policy, with the objective of facilitating the translation of such research to policy and practice; b) A community disparities track to enable postdoctoral fellows to develop and enhance skills in working with communities and engaging in community-based participatory research at institutions where these skills are present. Research emanating from the CRMH's Kellogg Health Scholars Program emphasizes the elimination of health disparities through community-based participatory research approaches and interdisciplinary approaches to developing solutions to health disparities. This strategy allows natural scientists, social scientists and community advocates to work collaboratively to develop new insights, and promote inter- institutional efforts to leverage the intellectual strength, diversity of ideas and energy from a multitude of faculty. The CRMH houses at least two post-doctoral minority fellows from this program every two years.

Specific Aim 5: To develop and evaluate a model that will enhance the recruitment and retention of minority populations participating in clinical trials.

Another hallmark of the CRMH achievements was been the implementation of a successful recruitment and retention model, sometimes referred to as a modified patient navigation model. This allowed CRMH research studies, and those research programs associated with the CRMH, to successfully recruit and retain minority and medically underserved participants in clinical trials, both treatment and prevention. Five studies exemplify our success in this area:

- 1) Centers for Medicare and Medicaid Services (CMS): This CRMH was one of six demonstration projects funded by CMS to investigate facilitated cancer screening services and patient navigation for Hispanic Medicare beneficiaries. This 4-year 5.4 million award is a tremendous effort towards addressing health disparities and health outcomes in this target population, essentially reducing systemic, cultural, educational, and logistical barriers that contribute to health disparities.
- 2) Women's Healthy Eating and Living (WHEL) study: The CRMH continues to work on the Women's Healthy Eating and Living study and published the main outcome of the study in July 2007. Of the seven clinical sites, the MD Anderson site recruited nearly 50% of the African- American, 30% of the Hispanic, and 50% of the Asian participants. The CRMH led the subanalysis of the minority cohort.
- 3) Susan G. Komen for the Cure (Local): Drs. Chilton, Bevers, Hajek, and Gor lead this study to compare minority women who participated vs. minority women who chose not to participate in a previous large breast cancer chemoprevention clinical trial. The goal of this project is to increase inclusion of minority populations into STELLAR through community outreach and education using identified predictors of non- participation and of participation of minority women in clinical trials. Data from this study will be used to design, pilot and test intervention using The SISTER Study (NIEHS).
- 4) The Sister Study: The CRMH joined forces with The Sister Study of the National Institute of Environmental Health Science, which is a breast cancer research project to

recruit minority women ages 35 - 74. The Sister Study is open to all women, ages 35 to 74, who have had a sister or sisters that have been diagnosed with breast cancer. The purpose of the study is to determine the role of gene environmental interaction in breast cancer. The role of the CRMH was to aid in increasing the number of minorities in the Sister Study.

5) Enhancing Minority Participation in Clinical Trials (EMPaCT) Phase 1: The EMPaCT Program established a national consortium to enhance participation of underrepresented minorities in clinical trials. Consortium members—University of Minnesota, University of Alabama at Birmingham, Johns Hopkins University, University of Texas-MD Anderson, and University of California-Davis—collaborated to develop, implement, and evaluate programs to promote participation in research studies across sites and minority populations. The community-based participatory research (CPBR) methodological framework will guide activities. In Phase 1, qualitative and quantitative data assessments among faculty and staff at each institution were conducted to identify barriers to participation in clinical trials among minority patients. Based on results of the Phase 1 assessments, a menu of interventions or programs to be developed for implementation in Phase 2 with the aim of increasing minority participation in cancer clinical trials at each institution. This project was funded by the National Institutes of Health.

B) Adaptation of the ACS Early Detection of Prostate Cancer Patient Decision Aid for Spanish-speaking Men

The major tasks for this work were:

- 1) determining the information needs of the target audience,
- 2) adaptation and translation of the English-language slide set into Spanish,
- 3) testing the adapted slides with Spanish-speaking men, and
- 4) creation of the final slide set and facilitator guide based on results of testing. Formative research in determining the information needs of the target audience and cultural issues was achieved with two complementary strategies. First, a search was performed to find literature on attitudes, beliefs, and information needs of Hispanics regarding prostate cancer screening or treatment. Medline, Embase, Cinahl, PyschInfo and Medline Plus were searched for articles published in 1994 or later. Keywords included "prostatic neoplasms," "treatment or therap.," "screen.," "Prostate-Specific Antigen or psa," and "Hispanic or Hispanic Americans." The search yielded 125 unique publications. Two research coordinators reviewed abstracts of the publications to determine relevance for this study. Relevant articles were then read and attitudes, beliefs, and information needs were abstracted from these. Major themes and a disposition of how these were addressed in the slide set are included in table 1.

The second source in determining needs of the target audience was results from the ACS's testing of a draft Spanish-language decision aid booklet. Findings were reviewed in report format and also in the form of conference calls between the project lead and ACS staff. The content of the ACS Spanish-language decision aid booklet closely mapped to the English side-set (attached as Appendix A). The findings were invaluable in making linguistically and culturally relevant modifications. For a disposition report of these modifications, see Appendix B. Translation of the English version of the slide set followed a rigorous method informed by guidelines for cross-cultural adaptation of self-report measures. Content of the English slides

was compared to content of the Spanish decision aid booklet as outlined in Appendix C. Any information needs identified in literature review that were not already addressed were added to the text of the slide set. Some content was rearranged for clarity. Next a certified translator at MD Anderson and a contracted external translation service independently translated the English text to Spanish. Bilingual study staff then reconciled the two versions into a draft Spanish slide set.

Table 1. Major themes related to Hispanic men's information needs about prostate cancer screening and cultural issues⁴⁻⁸

Area	Theme	Disposition		
Information Needs	Know little about prostate cancer or screening	Information included on these topics		
	Desire information on risk for prostate cancer	Risk information not included here, but higher risk populations urged to start screening discussions at earlier ages		
	Desire information on symptoms of prostate cancer	Information included on symptoms		
	Desire a diagram of the prostate	Diagram included		
	Desire facts about PSA	Facts on PSA included		
	Desire general information about DRE	General description of DRE included		
Cultural Issues	Disinterest in too much detail about DRE due to embarrassment	No photos included to minimize embarrassment		
	Hesitancy to initiate physician- patient relationship due to "machismo"	Talking to the doctor emphasized		
	Desire to defer decisions to the doctor	Language added emphasizing that this is the patients' decision		
	Desire for bright colors	Used blue and green vs. brown and orange		
	Desire for images of Hispanic patient and physician talking to each other	Used images of Hispanic patients throughout and images of patients consulting with doctors		
	Desire for women/families in the materials	Made reference to thinking about what is best for self and family in the decision; included photos of patients with family including wife		

A challenge during the research concerned the certified translations of the content. While accurate, the resulting translation lost the attention to literacy level of the original English slide

set. As such, we added a step where bilingual study staff edited the slides with attention to clarity and literacy level, comparing the certified translations and prior translation work done by the American Cancer Society. Readability Index was calculated with the INFLESZ Readability Evaluator. ¹⁰ Higher scores denote easier to read text. The Spanish slide set content had a Flesch-Szigiriszt Index (Spanish readability index) of 78.5 and INFLESZ rating of "fairly easy" on a scale of "very difficult, somewhat difficult, average, fairly easy, and very easy." This equates to text readable by a person with less than a high school education. ¹¹

Given that we had altered the translation method, we added a medical content expert review step. This Spanish document was reviewed by a medical content expert who is a native Spanish speaker and revised for clarity. Next, the Spanish document was back translated to English and reviewed by a medical content expert in English for consistency and accurateness. From there, the original English and back-translated versions were reviewed by the research team for inconsistencies or inaccuracies. All notes from the reviewers were incorporated into the English and Spanish slides by bilingual study staff. For an English version of the slides with notations regarding adaptations and their rationale see Appendix D. For a conceptual flowchart describing this translation and modification process, see Appendix E.

The translated slides were then compiled into mock-up slide sets that incorporated suggestions for images, layout, and color. These preliminary slides can be found in (Appendix F). In addition, alternate presentations were mocked-up for cognitive testing (Appendices G-J). These slide sets where then cognitive tested with 4 Hispanic men, all 45 years or older. The men were engaged in a "think aloud" exercise where they viewed the slides and then talked about the content in their own words. A cognitive interview guide was used for this purpose. It is attached as Appendix K and an English version is attached as Appendix L for reference. Using the guide and draft slides, a bilingual staff member interviewed the men, adding probes as needed to explore specific content and images. The content was revised based on testing feedback.

Concurrently with adaptation of the slide set, we prepared a Spanish-language evaluation instruments to determine the acceptability of materials and impact of the presentation on knowledge and decisional conflict related to prostate cancer screening. A focus group guide is attached as Appendix M and demographic (Appendix N), pre-test (Appendix O) and post-test (Appendix P) questionnaires. Measures include knowledge of prostate cancer and early detection, acceptability of the materials¹² (e.g., length, clarity, amount, and balance of information provided), and the low-literacy version of the decisional conflict scale¹³ translated into Spanish. English versions are included for reference (Appendices Q-T).

Focus groups were planned with Spanish-speaking Hispanic men who are candidates for prostate cancer screening. Although the original health educator we identified for the facilitator role left the institution, we were able to identify and train a Spanish-speaking Hispanic male health educator to serve as the focus group moderator. Spanish language educators from the Center for Health Equity and Evaluation Research (CHEER) were identified to translate for Dr. Curtis Pettaway during the focus group. A urologist, Dr. Pettaway was available to provide medical expertise and answer any questions from the focus group participants. Due to the departure of the principal investigator on this grant and the departure of several staff members in the Center for Health Equity and Evaluation Research, we were not able to access the database of Hispanic research participants. We were therefore unable to conduct the focus group evaluation.

The final step was to create the final products for the project: a slide set for use in community settings and a facilitator guide. Content finalized during testing was separated into on-screen

slide content and speaker notes. Preliminary images were replaced with stock photography, with rights purchased for multi-seat (unlimited users) and unlimited reproduction and print runs. The final PowerPoint presentation was separated into PDFs of the slides and facilitator guide of the speaker notes. Final slides have a Flesch-Szigiriszt Index of 80.52 (INFLESZ rating of "very easy") and speaker notes have a Flesch-Szigiriszt Index of 73.92 (INFLESZ rating of "fairly easy"). There were assembled into a final PDF portfolio along with instructions for how to use the PDF portfolio (Appendix U). This portfolio can be distributed to community screening programs.

KEY RESEARCH ACCOMPLISHMENTS

A. CRMH Infrastructure:

- A fortified CRMH infrastructure that supports a working network that develops culturally sensitive programs to support cancer awareness, cancer research, and training.
- A strong and sustained working network of community-based organizations; government agencies; research, educational, and medical institutions that address the disproportionate rates of cancer incidence and mortality in the Houston area through educational outreach, research, and procurement of needed services.
- An adept team of CRMH researchers and community health workers who conduct
 multiple types of health needs assessments and promote health education in the
 ethnic minority communities of Houston and surrounding areas.
- A multifaceted program that provides mentoring and extensive training for minority students at various educational levels pursuing careers in biomedical, epidemiological, and behavioral research.
- A holistic model of research that results in "science that benefits the community" and enhances the recruitment and retention of minority populations participating in clinical trials.

B. Adaptation of the ACS Early Detection of Prostate Cancer Patient Decision Aid for Spanish-speaking Men

- Identified information needs, attitudes, and beliefs of Hispanic men regarding early detection of prostate cancer
- · Adapted content to Spanish following a rigorous translation method
- Adapted reading level for suitability with lower literacy audiences
- Tested content with Hispanic men to refine for clarity and cultural appropriateness
- Created a facilitator's guide for community use
- Created Spanish language evaluation measures

REPORTABLE OUTCOMES

A. CRMH Infrastructure:

Grant Submissions:

• 6 grants applications submitted (2 funded; 4 not funded).

Manuscripts (See Appendix 8):

8 manuscripts in peer-reviewed journals; 1 national report.

Presentations and Abstracts:

 14 scientific oral or poster presentations by CRMH junior faculty during the reporting time period. This number does not include presentations made by the director of the CRMH, Dr. Lovell A. Jones or CRMH postdoctoral fellows.

Community Events:

• 12 community events for the reporting period (12% for recruitment; 62% for networking; 12% for promotion; 24% for collaboration).

Education Core:

Disparities in Health in America: Working Toward Social Justice (Fall Anchor Course)

- 147 Undergraduate and 8 Graduate students enrolled in the Fall 2011-2012.
- 173 Undergraduate and 8 Graduate students enrolled in the Fall 2012-2013.

Disparities in Health in America: Summer Workshop

- Summer 2012: 197 registered attendees
- Summer 2013: 183 registered attendees

PIPELINE Scientific Training Program

· 8 pipeline summer high school students

Environmental Health Summer Institute

8 teachers trained

University of Texas School of Public Health Interns or Practicum

4 MPH students and 1 DrPH student at CRMH

B. Adaptation of the ACS Early Detection of Prostate Cancer Patient Decision Aid for Spanish-speaking Men

The products from this project include:

- An adapted, Spanish language version of the ACS prostate cancer early detection decision aid prepared as a slide set.
- · A guide for facilitators to accompany the slide set.
- A PDF portfolio with instructions so that the materials may be distributed on a broad scale at the completion of the project.

CONCLUSION

Summarize the results to include the importance and/or implications of the completed research and when necessary, recommend changes on future work to better address the problem. A "so what section" which evaluates the knowledge as a scientific or medical product shall also be included in the conclusion of the report.

A. CRMH Infrastructure:

To summarize, the Center for Research on Minority Health (CRMH) at The University of Texas M. D. Anderson Cancer Center (M. D. Anderson) was established in 2000 as part of a Congressional mandate contained in the Omnibus Bill Public Law 106-113. In that Bill, Congress instructed M. D. Anderson Cancer Center to create a center of excellence whose focus would be on addressing health disparities in minority and medically underserved populations. In doing so, the CRMH became the first such congressionally mandated center in the nation outside of the federal government. The funds awarded by Congress were primarily designated for the creation of an infrastructure to position the new center's successful competition for external funding from various agencies interested in supporting research and educational efforts that address the unequal burden of disease in underserved populations. Today, the CRMH continues to be a unique entity whose focus on health disparities can be summarized in the phrase "Science That Benefits Community." The mission of the CRMH is to reduce, and ultimately eliminate cancer in ethnic minorities and the medically underserved through outstanding comprehensive programs in research, education, prevention and ultimately patient care. This is being accomplished through research and health promotion activities, cooperative initiatives, education and training and research collaborations. The IDM and prostate cancer screening component of this project will expand cutting edge research to ethnic minority communities and result in new, culturally appropriate interventions to promote informed decision making in various ethnic groups.

B. Adaptation of the ACS Early Detection of Prostate Cancer Patient Decision Aid for Spanish-speaking Men:

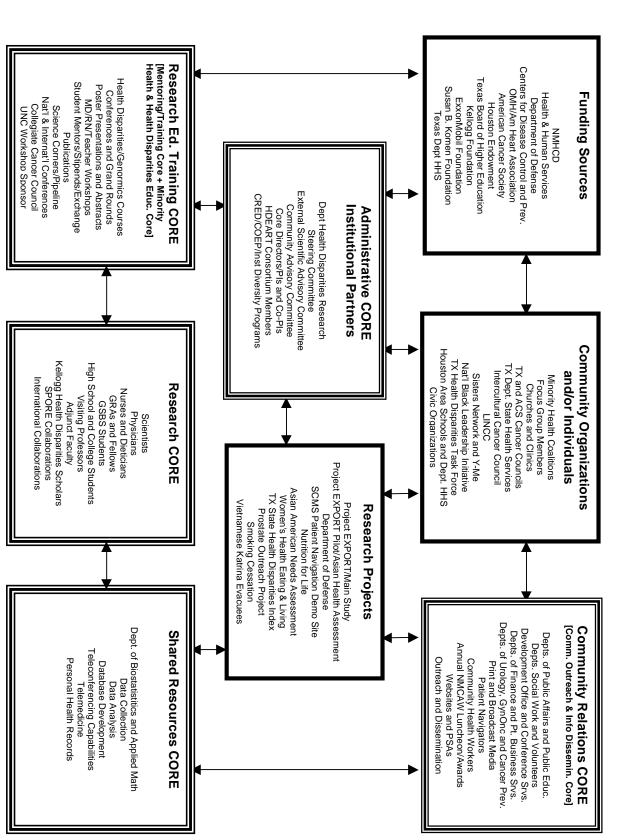
To summarize, this work has resulted in a presentation for use in community settings and an accompanying guide for educators that are linguistically and culturally appropriate to help Spanish-speaking Hispanic men make informed decisions about prostate cancer. This is very important as several guidelines emphasize the need for an informed decision making process regarding prostate cancer screening. While this process is not typically part of community screening events, these materials can assist these programs in ensuring that their participants make informed screening decisions.

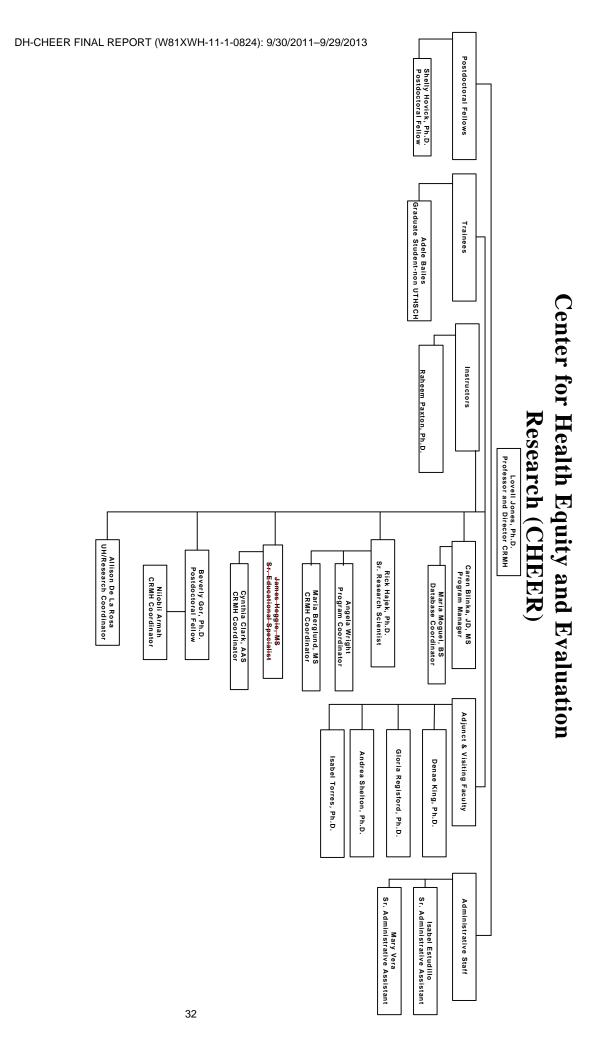
Several challenges in this work highlight the need for further study. First of all, results of cognitive testing indicated that men wanted information specific to Hispanic men. While this was relatively easy to find for incidence and mortality from prostate cancer, it was difficult to find information on probability of finding prostate cancer upon biopsy by PSA level specifically for Hispanic populations. It was also a challenge to find culturally-appropriate images for use in the slide set. Most available stock photography of physicians and male patients portrayed whites. Future updates to this presentation might consider production of such images with Hispanic men and Hispanic physicians. Readability can be challenging to assess in Spanish. While several methods of measuring readability give scores with general ratings of readability ease, a tool for assessing the American grade-level equivalent of Spanish text would be helpful.

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Appendix 1. Components of CRMH Model: Science that Benefits Community





Disparities in Health in America: Working Toward Social Justice Health Disparities Education, Awareness, Research & Training (HDEART) Consortium Center for Research on Minority Health **Consortium Representatives List**

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DISPARITIES IN HEALTH IN AMERICA: WORKING TOWARDS SOCIAL JUSTICE UNIVERSITY OF HOUSTON DOWNTOWN

SOS 3313 (Undergraduate) – Social Sciences – CRN 11993

Academic Building, Lecture Hall A-436, 4th Floor - One Main Street, Houston, TX 77002

2011 FALL SCHEDULE - REVISED

5:30 p.m. – 8:30 p.m., TUESDAY - WEEKLY August 23, 2011 – December 6, 2011

August 23, 2011 - Tuesday, 5:30-6:30 p.m., Academic Bldg., Lecture Hall A-436

"Overview of Class Requirements." – <u>Stacy Lloyd, Ph.D.</u>, - Kellogg Health Scholar, Center for Research on Minority Health, Department of Health Disparities Research, UT MD Anderson Cancer Center, Houston, TX.

6:30-6:45 - 15 Minute Break

August 23, 2011 - Tuesday, 6:45-7:45 p.m., Academic Bldg., Lecture Hall A-436

"Health Disparities in a Global Context." – <u>Professor Sir Michael Marmot, M.B.B.S., M.P.H., Ph.D.</u> – Chair of the WHO Commission on Social Determinants of Health, Director of the International Institute for Society and Health, and MRC Research Professor of Epidemiology and Public Health, University College, London. (*Video Presentation*) <u>Alexandra (Lexi)</u> <u>B. Nolen, Ph.D., M.P.H., (Moderator)</u> – Director of the Center to Eliminate Health Disparities, and Interim Director of the Global Health Program, University of Texas Medical Branch, Galveston, TX.

7:45 - 8:30 p.m. - Panel Discussion

August 30, 2011 - Tuesday, 5:30-6:30 p.m., Academic Bldg., Lecture Hall A-436

"Introduction to Health Disparities." P. Mona Khanna, M.D., M.P.H. – Medical Contributing Editor, Fox Chicago News, Chicago, IL.

6:30-6:45 p.m. - 15 Minute Break

August 30, 2011 - Tuesday, 6:45-7:45p.m., Academic Bldg., Lecture Hall A-436

"Caring for the Underserved, Disproportionate Share Providers and Institutions." Janet Phoenix, M.D., M.P.H. – Assistant Professor, Department of Health Policy, George Washington School of Public Health & Health Services, Washington, DC.

7:45 - 8:30 p.m. - Panel Discussion

September 6, 2011 - Tuesday, 5:30-6:30 p.m., Academic Bldg., Lecture Hall A-436

"TBN" " - <u>Laurence "Larry" J. Payne</u>. - President, Educational Excellence Resource Group of Harris County, Houston, TX.

6:30-6:45 p.m. - 15 Minute Break

"TBN" - Ann Christiano, M.S., B.A. – Professor and Frank Karel Chair in Public Interest Communications, Department of Public Relations, University of Florida College of Journalism & Communications, Gainesville, FL.

7:45 - 8:30 p.m. - Panel Discussion

September 13, 2011 - Tuesday, 5:30-6:30 p.m., Academic Bldg., Lecture Hall A-436

"Assessing and Addressing Asian American Health in Houston." - <u>Beverly J. Gor., Ed.D., R.D., L.D., C.D.E.</u>, Texas Health Disparities Fellow, Center for Research on Minority Health, Division of Cancer Prevention & Population Sciences, Department of Health Disparities Research, M.D. Anderson Cancer Center, Houston, TX. <u>Selina Ahmed, Ph.D., M.Sc., B. Sc.</u>, Associate Professor, College of Liberal Arts & Behavioral Sciences, Department of Human Services & Behavioral Sciences, Center for Research on Minority Health. <u>Luceli C. Cuasay, M.P.H., Dr.P.H.</u>, Senior Biostatistician, Westat Research Corporation.

6:30-6:45 p.m. - 15 Minute Break

September 13, 2011 - Tuesday, 6:45-7:45 p.m., Academic Bldg., Lecture Hall A-436

"Market or Social Justice: Implications for Health and Health Care." – <u>Nicholas Iammarino, Ph.D, C.H.E.S.</u> – Professor and Chairman, Department of Kinesiology, Rice University, Houston, TX. (confirmed)

7:45 - 8:30 p.m. - Panel Discussion

September 20, 2011 - Tuesday, 5:30-6:30 p.m., Academic Bldg., Lecture Hall A-436

"Cultural Tailoring for Health Promotion Program." - <u>Kenneth Resnicow, Ph.D.</u>, Professor, University of Michigan, School of Public Health, Ann Arbor, MI.

6:30-6:45 p.m. - 15 Minute Break

September 20, 2011 – Tuesday, 6:45-7:45 p.m., Academic Bldg., Lecture Hall A-436

"Pop Quiz"

7:45 - 8:30 p.m. - Panel Discussion

September 27, 2011 - Tuesday, 5:30-6:30 p.m., Academic Bldg., Lecture Hall A-436

"Using Ethnogenetic Layering to Illuminate the Genetics of Health Disparities." - Fatimah Jackson, Ph.D., Professor of Biological Anthropology, Director of Institute of African American Research, University of North Carolina at Chapel Hill, NC.

6:30-6:45 p.m. - 15 Minute Break

September 27, 2011 - Tuesday, 6:45-7:45 p.m., Academic Bldg., Lecture Hall A-436

"Why We Have Not Solved the Problems of Health Disparities? Why We Need New Approaches?" – William (Bill) Jenkins, Ph.D., M.P.H. – Consulting Epidemiologist, University of North Carolina, Chapel Hill, NC.

7:45 - 8:30 p.m. - Panel Discussion

October 4, 2011 - Tuesday, 5:30-6:30 p.m., Academic Bldg., Lecture Hall A-436 RESEARCH PAPER TOPICS DUE IN TO DR. LOVELL JONES

"Developing Students and Faculty in Conducting Health Disparities Education and Research." - <u>Jeffery J. Guidry, Ph.D.</u>, Associate Professor, Texas A&M University, Department of Health & Kinesiology, College Station, TX. (*Tentative*)

6:30-6:45 p.m. - 15 Minute Break

October 4, 2011 - Tuesday, 6:45-7:45p.m., Academic Bldg., Lecture Hall A-436

"Ancestry, Health & Disease: Placing Genetic Susceptibility into Context." – <u>Rick Kittles, Ph.D.</u>, Associate Professor, University of Illinois at Chicago, Chicago, IL.

7:45 - 8:30 p.m. - Panel Discussion

October 11, 2011 - Tuesday, 5:30-6:30 p.m., - Mid Term Exams Distributed – Academic Bldg., Lecture Hall A-436

"How to Market the Most Dangerous Consumer Product in the World to Minorities." - <u>Joel Dunnington, M.D.</u> – Professor of Radiology, Director, GI Radiology, The University of Texas MD Anderson Cancer Center, Houston, TX.

6:30-6:45 p.m. - 15 Minute Break

October 11, 2011 - Tuesday, 6:45-7:45 p.m., Academic Bldg., Lecture Hall A-436

"Community Model for Eliminating Disparities: Triangulation of Theory, Data and Practice." - Robert G. Robinson, M.S.W., Dr.P.H. – Associate Director Emeritus, Public Health Consultant, Atlanta, GA.

7:45 - 8:30 p.m. - Panel Discussion

October 18, 2011 - Tuesday, 5:30-6:30 p.m., - MID TERM EXAM DUE

"Narrowing the Gap Through Attention to Values and Ethics in Public Health Risk Assessment." - Colin L. Soskolne, Ph.D., F.A.C.E. Department of Public Health Sciences, School of Public Health, University of Alberta, Edmonton, Alberta, Canada.

6:30-6:45 p.m. - 15 Minute Break

October 18, 2011 - Tuesday, 6:45-7:45 p.m., Academic Bldg., Lecture Hall A-436

"The Impact of Culture on Health Disparities: A Research Methodology Emerges." – <u>Janice A. Chilton, Dr.P.H.,</u>
<u>M.C.H.E.S.</u>, Instructor, Center for Research on Minority Health, Division of Cancer Prevention & Population Sciences,
Department of Health Disparities Research, M.D. Anderson Cancer Center, Houston, TX.

7:45 - 8:30 p.m. - Panel Discussion

October 25, 2011 - Tuesday, 5:30-6:30 p.m., Academic Bldg., Lecture Hall A-436

"Population Science, Health Outcomes & Behavior." - Cathy D. Meade, Ph.D., R.N., F.A.A.N., Professor, USF College of Medicine, Dept. of Oncologic Sciences, H. Lee Moffitt Cancer Center & Research Institute, Tampa, FL.

6:30-6:45 p.m. - 15 Minute Break

October 25, 2011 - Tuesday, 6:45-7:45 p.m., Academic Bldg., Lecture Hall A-436

"Health Disparities in Palliative Care from Developing Nations to Minority Communities." – <u>Isabel Torres, Dr.P.H.,</u>
Associate Professor, University of Houston, Graduate College of Social Work, Dorothy I. Height Center for Health Equity Evaluation Research, Houston, TX.

7:45 - 8:30 p.m. - Panel Discussion

November 1, 2011 - Tuesday, 5:30-6:30 p.m., Academic Bldg., Lecture Hall A-436

"Genetic Education for Native Americans." – <u>Linda Burhansstipanov, Dr.P.H., M.S.P.H.,</u> Grants Director, Native American Cancer Research, and *Lynne Bemis, Ph.D.*, Faculty Member, University of Colorado Health Sciences Center, Denver, CO.

6:30-6:45 p.m. - 15 Minute Break

November 1, 2011 - Tuesday, 6:45-7:45p.m., Academic Bldg., Lecture Hall A-436

"Genetic Education for Native Americans." – <u>Linda Burhansstipanov</u>, <u>Dr.P.H.</u>, <u>M.S.P.H.</u>, Grants Director, Native American Cancer Research, and <u>Lynne Bemis</u>, <u>Ph.D.</u>, Faculty Member, University of Colorado Health Sciences Center, Denver, CO.

7:45 - 8:30 p.m. - Panel Discussion

University of Houston Downtown - Fall 2011 REVISED: 9/9/14

November 8, 2011 - Tuesday, 5:30-6:30 p.m., Academic Bldg., Lecture Hall A-436

"Disaster Navigators – A Community Based Participatory Research Model to Bolster Gulf Coast Community Resilience." – Maureen Lichtveld, M.D., M. P. H. – Professor & Chair, Freeport McCoRan of Environmental Policy, Tulane University, New Orleans, LA.

6:30-6:45 p.m. - 15 Minute Break

November 8, 2011 - Tuesday, 6:45-7:45 p.m., Academic Bldg., Lecture Hall A-436

"Exploring the Social and Physical Determinants of Cancer Risk in Galena Park, TX through Comparative Spatial Analysis in a GIS Environment." – <u>Demetrice R. Jordan, B.S.</u>, Student Intern, & <u>Denae King, Ph.D.</u>, Adjunct Assistant Professor, Center for Research on Minority Health, The University of Texas MD Anderson Cancer Center, Houston, TX.

7:45 - 8:30 p.m. - Panel Discussion

November 15, 2011 - Tuesday, 5:30-6:30 p.m., Academic Bldg., Lecture Hall A-436

"The Role of Health Communication in Reducing Health Disparities." – Shelly R. Hovick, Ph.D., Kellogg Health Scholar Postdoctoral Fellow, Center for Research on Minority Health, The University of Texas MD Anderson Cancer Center, Houston, TX.

6:30-6:45 p.m. - 15 Minute Break

November 15, 2011 - Tuesday, 6:45-7:45 p.m., Academic Bldg., Lecture Hall A-436

"Preventing Disparities in Cancer Screening Among Vulnerable Populations: Lessons from National Trends." - Patricia Y. Miranda, Ph.D., M.P.H. — Assistant Professor of Health Policy & Administration, The Pennsylvania State University, University Park, PA.

7:45 - 8:30 p.m. - Panel Discussion

November 22, 2011 - Tuesday, 5:30-6:30 p.m., Academic Bldg., Lecture Hall A-436

"TBN" – Guadalupe Palos, R.N., L.S.M.W., Dr.P.H. - Manager, Clinical Protocol Administration, Cancer Survivorship, The University of Texas MD Anderson Cancer Center, Houston, TX.

6:30-6:45 p.m. - 15 Minute Break

November 22, 2011 - Tuesday, 6:45-7:45 p.m., Academic Bldg., Lecture Hall A-436

"TBN" – <u>Carl V. Hill, Ph.D., M.P.H.</u> – Study Center Project Officer, National Children's Study, Eunice Kennedy Shriver National Institute of Child Health & Human Development (NICHD), NIH, Bethesda, MD. (CANCELED)

7:45 - 8:30 p.m. - Panel Discussion

November 29, 2011 - Tuesday, 5:30-6:30 p.m., Academic Bldg., Lecture Hall A-436 FINAL EXAMS DISTRIBUTED AND RESEARCH PAPERS DUE

"Du Bois and the Social Determinants of Health: A View of the Veil from this Century." - <u>Arthur McFarlane II</u>, Asthma Program Director, Colorado Department of Public Health & Environment, Denver, CO.

6:30-6:45 p.m. - 15 Minute Break

November 29, 2011 - Tuesday, 6:45-7:45 p.m., Academic Bldg., Lecture Hall A-436

"Final Exam Overview" – LaKeisha Batts, Ph.D., Postdoctoral Fellow, Center for Health Equity and Evaluation Research, Department of Health Disparities Research, UT MD Anderson Cancer Center, Houston, TX.

7:45 - 8:30 p.m. - Panel Discussion

December 3, 2011 - LAST DAY OF CLASSES

December 6, 2011, Tuesday, 5:30-6:30 p.m. - FINAL EXAMS DUE TO BE TURNED IN

December 16, 2011 - FINAL COURSE GRADES DUE - University of Houston Downtown

Local Speakers

Out-of-Town Speakers

DISPARITIES IN HEALTH IN AMERICA: WORKING TOWARDS SOCIAL JUSTICE TEXAS SOUTHERN UNIVERSITY

Barbara Jordan-Mickey Leland/Public Affairs Bldg. Auditorium, 1st Floor, Rm. 108 **HSHA 414 (Undergraduate)**

FALL 2012 COURSE SCHEDULE 5:30 p.m. – 8:30 p.m., TUESDAY - WEEKLY August 28 – December 15, 2012

August 28, 2012 - Tuesday, 5:30-6:30 p.m., Auditorium, 1st Floor, Rm. 108

"Overview of Class Requirements." – <u>Lovell A. Jones, Ph.D.</u>, Director & Professor, Dorothy I. Height Center for Health Equity and Evaluation Research, Division of Cancer Prevention & Population Sciences, The University of Texas MD Anderson Cancer Center/University of Houston, Houston, TX.

6:30-6:45 - 15 Minute Break

August 28, 2012 - Tuesday, 6:45-7:45 p.m., Auditorium, 1st Floor, Rm. 108

"Health Disparities in a Global Context." – Professor Sir Michael Marmot, M.B.B.S., M.P.H., Ph.D., Chair of the WHO Commission on Social Determinants of Health, Director of the International Institute for Society and Health, and MRC Research Professor of Epidemiology and Public Health, University College, London. (Video Presentation). Alexandra (Lexi) B. Nolen, Ph.D., M.P.H., (Moderator) Director, Center to Eliminate Health Disparities in the Division of Health Policy and Legislative Affairs, Associate Executive Director, Coordinating Center for Global Health, The University of Texas Medical Branch, Galveston, TX.

7:45 - 8:30 p.m. - Panel Discussion

September 04, 2012 - Tuesday, 5:30-6:30 p.m., Auditorium, 1st Floor, Rm. 108

"Social Determinants of Health and Health Disparities." – <u>Larry E. Laufman, Ed.D.</u>, Director of Research, Section of General Internal Medicine, Department of Internal Medicine, Baylor College of Medicine, Houston, TX.

6:30-6:45 p.m. - 15 Minute Break

September 04, 2012 - Tuesday, 6:45-7:45p.m., Auditorium, 1st Floor, Rm. 108

"Understanding Health Disparities in Texas: Truth or Paradox?" - <u>Karl Eschbach, Ph.D.</u>, Professor, Department of Internal and Preventive Medicine & Community Health Division of Geriatric Medicine, Director of Population Research, Sealy Center on Aging, The University of Texas Medical Branch, Galveston, TX.

7:45 - 8:30 p.m. - Panel Discussion

September 11, 2012 - Tuesday, 5:30-6:30 p.m., Auditorium, 1st Floor, Rm. 108

"Universal Health Care Legislations, Political Polarization, & Social Disparities in Access to Health Care: Evidence from Fifty American States." - Ling Zhu, Ph.D., Assistant Professor, Department of Political Science & The Master of Public Administration Program, University of Houston, Houston, TX.

6:30-6:45 p.m. - 15 Minute Break

September 11, 2012 - Tuesday, 6:45-7:45 p.m., Auditorium, 1st Floor, Rm. 108

"Social or Political Determinants: What is it About Americans?" – <u>John Lunstroth, L.L.M., M.P.H.</u>, Research Professor, Health Law & Policy Institute, University of Houston Law Center, Houston, TX.

7:45 - 8:30 p.m. - Panel Discussion

September 18, 2012 - Tuesday, 5:30-6:30 p.m., Auditorium, 1st Floor, Rm. 108

"Market or Social Justice: Implications for Health & Health Care." - Nicholas K. Iammarino, Ph.D., C.H.E.S., Professor of Health Sciences, Chair, Department of Kinesiology, Rice University, Houston, TX.

6:30-6:45 p.m. - 15 Minute Break

September 18, 2012 - Tuesday, 6:45-7:45 p.m., Auditorium, 1st Floor, Rm. 108

"Health Care – A Right, Privilege, or Gratuity." – <u>Ira C. Colby, D.S.W., L.C.S.W.</u>, Dean and Professor of Social Work, Graduate College of Social Work, University of Houston, Houston, TX.

7:45 - 8:30 p.m. - Panel Discussion

September 25, 2012 - Tuesday, 5:30-6:30 p.m., Auditorium, 1st Floor, Rm. 108

"Give Me Your Tired, Your Poor, Your Huddled Masses: Smoking In The United States And Its Relations With Race/Ethnicity, Socioeconomic Status, And Neighborhood Characteristics." – <u>Lorraine R. Reitzel, Ph.D.</u>, Assistant Professor, Department of Health Disparities Research, The University of Texas MD Anderson Cancer Center, Houston, TX.

6:30-6:45 - Questions and Answers

6:45-7:00 p.m. - 15 Minute Break

September 25, 2012 – Tuesday, 7:00-8:15 p.m., Auditorium, 1st Floor, Rm. 108

"How to Market the Most Dangerous Consumer Product in the World to Minorities." - <u>Joel Dunnington, M.D.,</u> Professor of Radiology, Director, GI Radiology, The University of Texas MD Anderson Cancer Center, Houston, TX.

8:15 - 8:30 p.m. - Questions & Answers

October 02, 2012 - Tuesday, 5:30-6:30 p.m., Auditorium, 1st Floor, Rm. 108

"The Impact of Culture Diversity on Health Disparity: A Research Methodology Emerges." – <u>Janice A. Chilton, Dr.P.H., M.C.H.E.S.</u>, Instructor, Dorothy I. Height Center for Health Equity and Evaluation Research, Division of Cancer Prevention & Population Sciences, and Department of Health Disparities Research, The University of Texas MD Anderson Cancer Center, Houston, TX.

6:30-6:45 p.m. - 15 Minute Break

October 02, 2012 - Tuesday, 6:45-7:45 p.m., Auditorium, 1st Floor, Rm. 108

"Narrowing the Gap Through Attention to Values and Ethics in Public Health Risk Assessment." - Colin L. Soskolne, Ph.D., F.A.C.E., Department of Public Health Sciences, School of Public Health, University of Alberta, Edmonton, Alberta, Canada.

7:45 - 8:30 p.m. - Panel Discussion

October 9, 2012 - Tuesday, 5:30-6:30 p.m., Auditorium, 1st Floor, Rm. 108

Research Paper Topics Due into Dr. Lovell Jones

"Ancestry, Health & Disease: Placing Genetic Susceptibility into Context." – <u>Rick Kittles, Ph.D.</u>, Associate Professor, Associate Director, Cancer Center, University of Chicago, Chicago, IL.

6:30-6:45 p.m. - 15 Minute Break

October 9, 2012 - Tuesday, 6:45-7:45p.m., Auditorium, 1st Floor, Rm. 108

"Ancestry, Health & Disease: Placing Genetic Susceptibility into Context." – <u>Rick Kittles, Ph.D.</u>, Associate Professor, Associate Director, Cancer Center, University of Chicago, Chicago, IL.

7:45 - 8:30 p.m. - Panel Discussion

October 16, 2012 - Tuesday, 5:30-6:30 p.m., - Auditorium, 1st Floor, Rm. 108

Mid Term Exams Distributed

"Genes, History and the Development of Autoimmunity." – <u>John D. Reveille, M.D.</u>, Professor of Internal Medicine, Linda and Ronny Finger Foundation Distinguished Chair in Neuroimmunologic Disorders, George S. Bruce, Jr. Professorship In Arthritis & Other Rheumatic Diseases, Director Of The Division Of Rheumatology And Clinical Immunogenetics, University of Texas Health Science Center, Houston, TX.

6:30-6:45 p.m. - 15 Minute Break

October 16, 2012 - Tuesday, 6:45-7:45 p.m., Auditorium, 1st Floor, Rm. 108

"Using Ethnogenetic Layering to Illuminate the Genetics of Health Disparities." - Fatimah Jackson, Ph.D., Professor of Biological Anthropology, Director of Institute of African American Research, University of North Carolina at Chapel Hill, NC.

7:45 - 8:30 p.m. - Panel Discussion

October 23, 2012 - Tuesday, 5:30-6:30 p.m., - Auditorium, 1st Floor, Rm. 108 Mid Term Exams Due

"Genetic Education for Native Americans." – <u>Linda Burhansstipanov</u>, <u>Dr.P.H.</u>, <u>M.S.P.H.</u>, Grants Director, Native American Cancer Research, and <u>Lynne Bemis</u>, <u>Ph.D.</u>, Professor & Chair of the Department of Biological Sciences, University of Minnesota at Duluth, Duluth, MN.

6:30-6:45 p.m. - 15 Minute Break

October 23, 2012 - Tuesday, 6:45-7:45 p.m., Auditorium, 1st Floor, Rm. 108

"Genetic Education for Native Americans." – <u>Linda Burhansstipanov</u>, <u>Dr.P.H.</u>, <u>M.S.P.H.</u>, Grants Director, Native American Cancer Research, and <u>Lynne Bemis</u>, <u>Ph.D.</u>, Professor & Chair of the Department of Biological Sciences, University of Minnesota at Duluth, Duluth, MN.

7:45 - 8:30 p.m. - Panel Discussion

October 30, 2012 - Tuesday, 5:30-6:30 p.m., Auditorium, 1st Floor, Rm. 108

"The Changing Face of Houston: Tracking the Economic and Demographic Transformations through 31 Years of Surveys." – <u>Stephen Klineberg, Ph.D.</u>, Professor of Sociology & Co-Director of the Kinder Institute for Urban Research, Rice University, Houston, TX.

6:30-6:45 p.m. - 15 Minute Break

October 30, 2012 - Tuesday, 6:45-7:45 p.m., Auditorium, 1st Floor, Rm. 108

"Highlights of the Health of Houston 2010 Survey" – <u>Stephen H. Linder, Ph.D.</u>, Professor & Associate Director of the Institute for Health Policy, The University of Texas Health Science Center, Houston, TX.

7:45 - 8:30 p.m. - Panel Discussion

November 6, 2012 - Tuesday, 5:30-6:30 p.m., Auditorium, 1st Floor, Rm. 108

"Linking the Changing Faces of U.S. Latinos to Health Outcomes: Is There Equity for All" – Guadalupe Palos, R.N., L.S.M.W., Dr.P.H., Manager, Clinical Protocol Admin, Cancer Survivorship, The University of Texas MD Anderson Cancer Center, Houston, TX.

6:30-6:45 p.m. - 15 Minute Break

November 6, 2012 - Tuesday, 6:45-7:45p.m., Auditorium, 1st Floor, Rm. 108

"Assessing and Addressing Asian American Health in Houston." - Beverly J. Gor., Ed.D., R.D., L.D., C.D.E., Texas Health Disparities Fellow, Dorothy I. Height Center for Health Equity & Evaluation Research, Division of Cancer Prevention & Population Sciences, The University of Texas MD Anderson Cancer Center, Houston, TX. Selina Ahmed, Ph.D., M.Sc., B. Sc., Associate Professor, College of Liberal Arts & Behavioral Sciences, Department of Human Services & Behavioral Sciences, Dorothy I. Height Center for Health Equity & Evaluation Research.

7:45 - 8:30 p.m. - Panel Discussion

November 13, 2012 - Tuesday, 5:30-6:30 p.m., Auditorium, 1st Floor, Rm. 108

"Community-Based Participatory Research for Cancer Prevention and Control Research: Methods and Outcomes." – Chanita Hughes Halbert, Ph.D., Professor & Endowed Chair, Medical University of South Carolina, Department of Psychiatry & Medical Sciences, Charleston, SC.

6:30-6:45 p.m. - 15 Minute Break

November 13, 2012 - Tuesday, 6:45-7:45 p.m., Auditorium, 1st Floor, Rm. 108

"Minority Participation In Clinical Trials And NCI's Strategies To Monitor Success." - Ernest Hawk, M.D., M.P.H., Vice President & Division Head, Division of Cancer Prevention & Population Science, The University of Texas MD Anderson Cancer Center, Houston, TX.

7:45 - 8:30 p.m. - Panel Discussion

November 20, 2012 - Tuesday, 5:30-6:30 p.m., Auditorium, 1st Floor, Rm. 108

"The Role of Health Communication in Reducing Health Disparities." – Shelly R. Hovick, Ph.D., Population Sciences Fellow, Behavioral Science, The University of Texas MD Anderson Cancer Center, Houston, TX.

6:30-6:45 p.m. - 15 Minute Break

November 20, 2012 - Tuesday, 6:45-7:45 p.m., Auditorium, 1st Floor, Rm. 108

"Health Literacy Meets Social Justice: Words do Count!" - <u>Cathy D. Meade, Ph.D., R.N., F.A.A.N.</u>, Senior Member and Professor, Population Science Health Outcomes & Behavior, Moffitt Cancer Center, University of South Florida, Tampa, FL.

7:45 - 8:30 p.m. - Panel Discussion

November 27, 2012 - Tuesday, 5:30-6:30 p.m., Auditorium, 1st Floor, Rm. 108

All Research Papers Are Due

"Cultural Competence Versus Cultural Humility – What It Means To Me?" - <u>Jeffery J. Guidry, Ph.D.</u>, Associate Professor, Texas A&M University, Department of Health & Kinesiology, College Station, TX.

6:30-6:45 p.m. - 15 Minute Break

November 27, 2012 - Tuesday, 6:45-7:45 p.m., Auditorium, 1st Floor, Rm. 108 **All Research Papers Are Due**

"Health Disparities in Palliative Care." – <u>Isabel Torres, Dr.P.H.</u>, - Associate Professor, University of Houston Graduate College of Social Work, Dorothy I. Height Center for Health Equity and Evaluation Research, The University Texas MD Anderson Cancer Center, Houston, TX.

7:45 - 8:30 p.m. - Panel Discussion

December 4, 2012- Tuesday, 5:30-6:30 p.m., Auditorium, 1st Floor, Rm. 108 Final Exams Distributed

"Exploring the Social and Physical Determinants of Cancer Risk in Galena Park, TX through Comparative Spatial Analysis in a GIS Environment." – Demetrice R. Jordan, M.A., B.S., Predoctoral Student, & Denae King, Ph.D., - Adjunct Assistant Professor, Dorothy I. Height Center for Health Equity and Evaluation Research, The University of Texas MD Anderson Cancer Center, Houston, TX.

6:30-6:45 p.m. - 15 Minute Break

December 4, 2012- Tuesday, 6:45-7:45 p.m., Auditorium, 1st Floor, Rm. 108

"Disaster Navigators – A Community Based Participatory Research Model to Bolster Gulf Coast Community Resilience." – Maureen Lichtveld, M.D., M. P. H., Professor & Chair, Freeport McCoRan of Environmental Policy, Tulane University, New Orleans, LA.

7:45 - 8:30 p.m. - Panel Discussion



BIENNIAL SYMPOSIUM

ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

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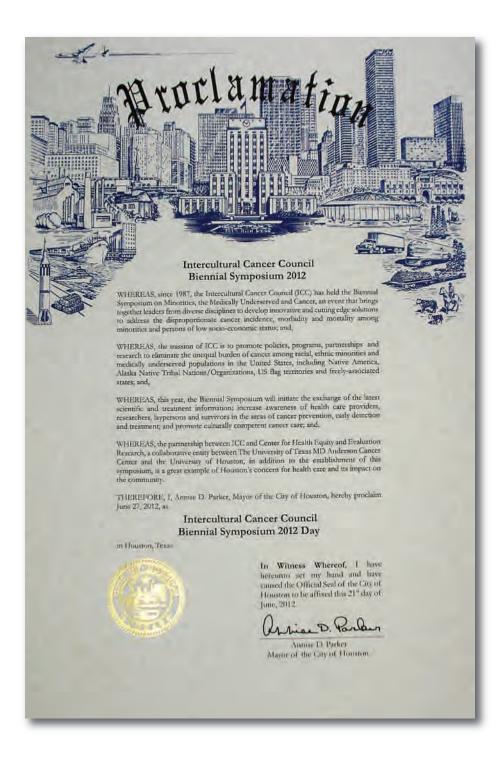
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Empowering Communities in the Era of Health Care Reform





Empowering Communities in the Era of Health Care Reform



STATE OF TEXAS OFFICE OF THE GOVERNOR

Greetings:

As Governor of Texas, it is my pleasure to welcome everyone to Houston for the Biennial Symposium on Minorities, the Medically Underserved and Health Equity.

Since its conception in 1987 under the guiding hand of the Intercultural Cancer Council, this symposium has drawn attention to the disproportionate incidence of cancer morbidity among minorities and the medically underserved. By bringing together leaders from diverse disciplines, it has promoted competent cancer care for all cultures.

As you celebrate its 25th anniversary, the symposium continues to spread awareness and educate health care providers, researchers, survivors, and other interested parties in the areas of primary and secondary cancer prevention, early detection, and treatment. I commend you all for your work to improve the quality of health care for all Americans.

First Lady Anita Perry joins me in sending best wishes.

Sincerely,

RICK PERRY
GOVERNOR



Empowering Communities in the Era of Health Care Reform



We have come a long way since the first Symposium in Houston in 1987. At that time we launched National Minority Cancer Awareness Week (NMCAW) to bring attention to the glaring cancer disparities faced by ethnic minorities and the medically underserved, wondering if this nation cared or even noticed. Right after the 11th Biennial Symposium on Minorities, the Medically Underserved & Cancer, the Journal of the American Medical Association stated that even with all the focus on health disparities, the gap remained basically the same, and in some cases was getting wider. Despite all of the advancements, we were missing something vital in our fight against health disparities. It was time for reassessment. What seemed to be missing was the true involvement of everyone, "All Americans." That sense of inclusiveness had been key to the success of the previous Symposia, but we were still missing something – the fact that health care access alone will not solve the issue of health disparities. Recently the Symposium has undergone another change - its name is now the Biennial Symposium on Minorities, the Medically Underserved & Health Equity. We acknowledge that to solve the issue of cancer disparities, we must take a positive approach, we must consider the effects of other diseases and environmental issues, and we must involve a broad spectrum of social, academic, and biomedical disciplines.

Again, the 12th Biennial is attracting attendees and speakers from all corners of America, but this time, from all disciplines. We've revised the format to fit our broadened vision. When the 1st Biennial took place, I was asked who would be the target audience, and I responded "Everybody." The questioner replied that everyone could not attend, that not everyone would understand what we were attempting to do, that not everyone would understand what was being said. The questioner said we needed to have a target audience of health care providers – physicians, nurses, allied health professionals – we couldn't invite everyone. Today, our biopsychosocial approach serves as a model by which others research health issues in a wide range of cultures and communities. But there is still much work to be done, as illustrated by the continuing gaps in health care: inequities in access, medical treatment, prevention and screening, and participation in clinical trials. And once again, it is time for us to climb back out on that limb, to focus our attention on the next level. In doing so, we have returned home to where it all started, Houston, Texas. Change does not come easy and does not come without risk. However, risk has always been our middle name, and we will not retreat from it.

At the 11th Symposium, we rededicated ourselves to the principles established at the 1st. Now, with the move back to our original site, our new format emphasizes health equity, strives to focus on the positive and to minimize the negative, and provides the tools necessary to assess where we are going in the age of health reform. Because no matter what the U.S. Supreme Court decides about the Affordable Care Act, change is going to come. With our Plenary Session entitled "Mapping the Future of Science and Service toward Health Equity in the Era of Health Reform," we will discuss where we're going from here. We are determined to reenergize and be the catalyst for change, to become a force that truly brings together those who have the resources for change and those who are in need of those resources.

It has been almost three decades since I first thought of having a meeting that would be like no other, that would include everyone. Our new format reaffirms that initial concept. It is my hope that as we continue into our third decade, someone will pick up the torch that so many of us have held high, and carry it across the finish line; that we substantially contribute to the creation of a society in which the health of a person is not related to skin color, religion, sexual orientation or socioeconomic status. I again challenge you to "Speak with One Voice," for if you don't, who will?

Lovell A. Jones, PhD

Founder, ICC Biennial Symposium Series Co-Founder, ICC



Empowering Communities in the Era of Health Care Reform



Time Flies -- Progress Crawls

Iwould like to start by thanking our Symposium Chair, Lee Buenconsejo-Lum, ICC members, network leadership, program and funding partners, staff and consultants of CHEER and the ICC, who have made this meeting a reality.

It is particularly nice to welcome community advocates, academic colleagues, students, representatives from community and faith-based organizations, policy-makers and of course, to those of you, who are veterans of previous biennial symposia, welcome back.

What better place to help address "Empowering Communities in the Era of Health Care Reform" than Houston, my hometown, where health and health care are frequently discussed topics and so much of our local lives and economy are dependent on it? Where Lovell and I have been able to support the efforts of many coming together through venues like the Biennial and the Intercultural Cancer Council. Where we each have been a part of academic research entities that have helped create some of our most remarkable medical advances. Where our public and private health care leadership struggle with resource allocation to address access, costs, efficiencies and if we are successful, health equity.

In welcoming participants to our last symposium themed, "Charting a New Course Together", I spoke to the benefit and responsibility of making the journey and working together. Many can argue that we have not quite seen the type of collective collaboration, or "togetherness" hoped for and that we have failed in some areas. Personally I think the stress and strains of the past few years have again opened us to the possibilities of doing it better. In research, we know it is imperative that we learn from our failures. For health equity, we must do the same.

There is not one-way to achieve health equity, but many. The ICC motto, "Speaking With One Voice" has for more than twenty years, demonstrated that by sharing your voice at these biennial gatherings, we can do more because each of you have, and I trust, will again return to your community and do more.

Why then do I suggest as we prepare for your participation in this celebratory biennial that you should be reminded that while "time flies" ... "progress crawls!" These seem disturbing truths today. Yet I remain optimistic because people in the community over and over again have demonstrated that they can use local resources, ingenuity, passion, and compassion to meet challenges. Maybe we should ask our communities to help empower us! After all, most of us learned to crawl before we learned to walk.

Armin D. Weinberg, PhD

Co-Founder, ICC



Empowering Communities in the Era of Health Care Reform



Aloha mai kākou, ;hola!, mabuhay and 안녕하세요,

On behalf of the Biennial Symposium Steering Committee and the Honorary Co-Chairs, I warmly welcome all participants to the 12th Biennial Symposium on Minorities, the Medically Underserved and Health Equity. This Symposium marks the 25th Anniversary of the Biennial Symposium series and features outstanding speakers, panel discussions, capacity-building workshops, success stories and opportunities for meaningful dialogue which will help lead us all forward in collaborative efforts to reduce health disparities and improve health equity for all of our populations. Additionally, the 10th Disparities in Health in America Workshop: Working Toward Social Justice will be held in conjunction with the Symposium, with many areas of overlap between the programs for academic credit, non-academic credit and professionals.

The Symposium theme is "Empowering Communities in the Era of Health Care Reform." True community engagement, advocacy and self-determination are critical to improving the health of our varied populations. We must take advantage of our strengths - our cultures, faith, community and convictions - and forge new partnerships utilizing the principles of kakou (inclusivity and sharing, working toward community well-being). With that in mind, the morning panels on Thursday-Saturday have been designed to discuss and challenge the status quo and foster dialogue on how to really include communities in the challenging work ahead. The Thursday afternoon Marketplace of Ideas encourages sharing of ideas among community-based organizations and other partners. Several opportunities exist on Friday afternoon, ranging from learning how scientists and academics are currently working with community partners to exploring the critical role that community leaders play in ensuring appropriate access to resources, screening and treatment in times of dire need. Successes will be celebrated on Saturday afternoon, followed by intense discussion on what is still needed to ensure communities can play their proper role in the health care systems in the U.S., Tribes, Territories and Pacific Island countries. Capacity building workshops will be held on Sunday morning, followed by hearing Community Voices from the Saturday breakout sessions.

The Symposium and the ICC also symbolize collaboration, community and caring. Special evening events, named lectureships, awards luncheons and dinners pay tribute to outstanding individuals and organizations whose work has aided others in the fight against cancer and health disparities. The accomplishments of these individuals and organizations are really a reflection of the work in which you – the community – have allowed them to participate. Please join us in celebration, come to greet old friends and make new ones. We round out the Symposium on Sunday with reflections and thoughts on next steps from our Honorary Symposium Co-Chairs – who have spent their careers ensuring we all have access to the tremendous opportunities before us this week. We are indeed thankful to be in the presence of such humble giants. I am also quite thankful for the dedicated staff and scientists at no less than five institutions who have worked long hours to make this Symposium a reality.

Each of us has special gifts. We hope this Symposium will bestow you with more, so that we can go forth, taking care of each other and doing what is right and good. It has been my honor serving as Symposium Chair and I look forward to meeting all of you.

Aloha kākou a e mālama pono,

Lee Ellen Buenconsejo-Lum, MD *Symposium Chair*

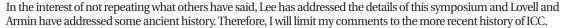


Empowering Communities in the Era of Health Care Reform

Greetings to My ICC Sisters and Brothers,

It would indeed be presumptuous of me to welcome you to your very own meeting, so may I begin with just a very warm aloha to all our ICC (Intercultural Cancer Council) sisters and brothers.

This 25th Anniversary ICC Biennium meeting is being held after a hiatus of many years because of the economy and other transition issues. I am happy to report that the ICC is alive, well and kicking at multiple levels.





Through the good offices of our co-founders Lovell Jones and Armin Weinberg, ICC has moved seamlessly from the Baylor College of Medicine to the University of Houston, where Lovell Jones is funding the new Center for Health Equity & Evaluation Research. This involves a whole slew of transitions for ICC. Firstly, the move is a huge step forward as we are also simultaneously obtaining our 501(c)(3) non-profit status. Secondly, we will be in a hospitable environment at the University of Houston, because Lovell's full time vocation and avocation is dealing with the social justice and health issues that ICC holds so dear. Thirdly, notwithstanding our name, ICC is broadening its focus to address all health issues not merely cancer. Thus, our new emphasis will be on all diseases (especially the chronic diseases) that afflict people of color. Fourthly, we have downsized our board to a new interim board which will set up a more self-sustaining permanent structure over the next few years.

Social justice – especially as it applies to health – is what we have historically done and what we must continue to do. Only then will we ever be able to achieve the World Health Organization's idealistic but achievable definition of health which is "A state of physical, mental, and social well-being, not merely the absence of disease and disability." When one studies the etymology of the word disease, its two components are dis (without) and ease.

Today, it is more evident that health in minority and underserved communities cannot be approached as a single monolithic issue, but one to which many societal factors contribute. Therefore, the ICC Biennial Symposium Series on Minorities, the Medically Underserved & Cancer has again evolved to meet the needs of the underserved, and become the ICC Biennial Symposium on Minorities, the Medically Underserved & Health Equity, whose theme for the 25th Anniversary is "Empowering Communities in the Era of Health Care Reform." This venue will be a platform for addressing the catalysts needed for making the changes that are required to effectively meet the health needs of people of color in general and underserved people in particular. I am particularly concerned about the funding for disparities in this era of health care reform. America is at a crossroads in addressing these issues. With the demographic changes that have taken place over the last 25 years, it is imperative that we do everything to reduce the health care gap. The 25th Anniversary will not only concentrate on the inequities in health care, but on viable solutions. Chronic diseases and their behavioral antecedents still relate inversely to education, income/social class and being white. Thus, we still need to aggressively address the societal cues that foster tobacco use and the occurrence of obesity and physical inactivity in low-income ethnic neighborhoods.

Lovell Jones (co-founder and perennial benefactor of ICC) is generously housing and nurturing ICC in his Center for Health Equity & Evaluation Research at the University of Houston. Pam Jackson, who has been with ICC from the very beginning, will be our new Interim Executive Director until such time as she helps us choose a permanent successor.

It would indeed be remiss of me not to thank a handful of people to whom ICC and I are inordinately indebted for their tremendous support during this transition time. In addition to Pam, Lovell, and Armin, I am especially indebted to my immediate predecessor the irreplaceable Jim Williams, Chair of this meeting Lee Buenconsejo-Lum, the indefatigable logistical genius Angela Wright and all the past chairpersons and leaders of ICC, many of whom I have consulted especially Susan Shinagawa.

Given our ongoing struggles over the last three decades that seem to extend into our future with health care reform, ICC must remember the words of Winston Churchill, "Know that this is not the end. It is not even the beginning of the end. But it is, perhaps, the end of the beginning."

At the expense of some necessary Indian overkill, I would like to most of all to thank all of you in the ICC membership, in as many languages as I can conceivably muster.

 $Thank\ you\ -Dhanyavad\ -Ngiyabonga\ -Gracias\ -Merci\ -Mahalo\ -Arigato\ -Danke\ -Salamat!$

Dileep G. Bal, MD, MS, MPH *Chair, ICC*

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Empowering Communities in the Era of Health Care Reform



Greetings:

On behalf of the Family of Dorothy I. Height, it is my distinct honor and privilege to welcome you to the "12th Biennial Symposium on Minorities, the Medically Underserved and Health Equity." We are so excited and extremely grateful that you have come to help "Celebrate a 25-Year of Legacy of Addressing Health Disparities." We appreciate your support for the 25th Anniversary of "Empowering Communities in the Era of Health Care Reform" and community health initiatives addressing cancer health inequities in an effort to improve access, screening, quality health care and human rights.

Twenty five years affords the governing body of the Intercultural Cancer Council (ICC) the opportunity to honor those organization, individuals, survivors, Federal agencies, and communities who have raised consciousness, demonstrated commitment, compassion, and competence that adds to the legacy of the exceptional leadership that Dorothy I. Height dedicated her life's work to. For nearly half a century, Dorothy I. Height gave leadership to the struggle for equality and human rights for all people. Her life exemplifies her passionate commitment for a just society and her vision of a better world. Dorothy Height made a difference in the lives of millions of individuals during her decades of public life as dream giver, earth shaker and crusader for human rights.

As we come together these next 5 days, we the family are convinced that collectively you can identify the solutions and strategies needed to further the mission of the ICC in our communities and to transform ourselves through harnessing our collective power. With your thoughts and ideas, commitment, research and collaboration, we look forward to continuing her legacy of access to health care and health equity for all people.

Sincerely,

Pamela M. Jackson, MS Interim Executor Director, Intercultural Cancer Council



Dorothy I. Height



Empowering Communities in the Era of Health Care Reform

MISSION STATEMENT

The Intercultural Cancer Council (ICC) promotes policies, programs, partnerships, and research to eliminate the unequal burden of cancer among racial and ethnic minorities and medically underserved populations in the United States, including Native America and Alaska Native Tribal Nations and Organizations and US flag territories and freely-associated states.

NEEDS and BACKGROUND

There is a disproportionate cancer incidence, morbidity, and mortality among minorities and persons of low socio-economic status in the United States and its associated tribal nations, territories and Pacific Island jurisdictions. Health disparities suffered by these groups have been documented through published reports. There is a critical need to develop knowledge and strategies to address this crisis with the leadership and full participation of the affected communities.

In 1987, the Biennial Symposium on Minorities and Cancer was launched in Houston, Texas to address this need. In 1995, with the launching of the Intercultural Cancer Council, the Symposium Series moved to Washington, D.C. and was renamed the Biennial Symposium on Minorities, the Medically Underserved & Cancer, in recognition that cancer was a national issue that needed to be on the American health agenda. Following the 2008 Biennial Symposium on Minorities, the Medically Underserved & Cancer, a decision was made to host regional meetings around the country, with plans to bring everyone back together in 2012.

Since cancer is only one of many health disparities faced by minority and underserved individuals, the 2012 meeting will not limit its discussion to cancer issues. It will be hosted by the Center for Health Equity & Evaluation Research (a joint venture of the University of Houston and the University of Texas MD Anderson Cancer Center) and the Intercultural Cancer Council.

GOALS

The goals of the Biennial Symposium series are to:

 Exchange the latest scientific and treatment information and to share strategies for reducing the disproportionate incidence of cancer morbidity and mortality among

- minorities and the medically underserved;
- Increase the awareness and enhance the competence of health care providers, researchers, laypersons and survivors in the areas of primary and secondary cancer prevention, early detection and treatment;
- Promote culturally competent cancer care and services and ethnically balanced research, especially clinical trials;
- Ensure that underserved populations are selectively targeted in the evolution of the Health Care Reform Act;
- Provide a comprehensive approach to the issue of health disparities;
- Provide attendees with a broad knowledge base related to a biopsychosocial approach in addressing health disparities.

THEME

"Empowering Communities in the Era of Health Care Reform"

OBJECTIVES

At the conclusion of the 12th Symposium, participants should be able to:

- Summarize the most current scientific information available about specific cancers and chronic diseases of particular concern in minority and medically underserved communities, including the impact of certain health and lifestyle factors;
- Discuss and demonstrate the importance and promotion of cancer and chronic disease prevention, early detection, timely and quality treatment, supportive and palliative care, and end of life issues;
- Identify community and state-level resources and available funding to reduce chronic disease and health disparities;
- Effectively communicate best or emerging practices which build community capacity to:
 - Advocate for new programs and policies to improve access to cancer and chronic disease preventive, screening, treatment and survivorship services;
 - Build and maintain effective partnerships and networks to prevent and control chronic disease in disparity populations;
 - Empower participants with knowledge, skills and connections to enhance their work with communities; and
 - Identify and access national and local organizations engaged in cancer- and chronic disease-related activities.

Empowering Communities in the Era of Health Care Reform

TARGET AUDIENCE

- Cancer survivors, community-based organizations (CBOs), specialists, family physicians, and scientists interested or involved in community-based cancer prevention and control programs for minorities and the medically underserved
- Students from minority or medically underserved communities seeking careers in cancer research and health care
- Community leaders, chaplains, business executives, educators, hospitals and clinic administrators, government and voluntary health agency program directors responsible for health promotion and disease prevention for persons who are at higher risk of cancer or other diseases due to economic, cultural, geographic, political, social, medical or other barriers
- National or local advocates for cancer survivors and the medically underserved; elected, appointed, or career government officials, public or private opinion leaders involved in biomedical research and health care reform policy
- Primary care, community and family physicians, oncologists, nurses, allied health professionals, health educators, community health workers, dietitians, social workers and other persons involved in the cancer care continuum

EDUCATIONAL METHODS

Educational methods include lectures, case presentations, technical and educational programs, panel discussions, program demonstrations, questions and answer sessions, networking activities, and oral and poster presentations

EVALUATION

A course evaluation form will provide participants with the opportunity to review each session and speaker, to identify future educational needs and to comment on any perceived commercial bias in the presentations. Exit surveys will be conducted to obtain feedback on organization, general content, workshops and exhibits, networking opportunities, and recommendations for the next Symposium. A post-Symposium survey will be used to assess changes in knowledge, attitudes, beliefs and behaviors and to what extent and how the information, materials and resources offered at the Symposium are being utilized by the participants.

ACKNOWLEDGEMENTS

The ICC Executive Committee and Governing Board gratefully acknowledge the generous funding support of the various agencies, organizations, corporations, and foundations for the 12th Biennial Symposium on Minorities, the Medically Underserved & Health Equity.

We wish to thank the many agencies, organizations, corporations, and foundations for lending their financial support to our participants. It is through their generosity that many of the students and our community partners are able to attend the 12th Biennial Symposium.

We also acknowledge the dedication of the Symposium staff and volunteers in making this event possible.

PRIVATE PARTNERS

American Association for Cancer Research
American Cancer Society
American Legacy Foundation
Amgen Oncology
C-Change
Dan L. Duncan Cancer Center at Baylor College
of Medicine

Herbert Irving Comprehensive Cancer Center IMAN Cosmetics
Johns Hopkins University
LIVESTRONG – Lance Armstrong Foundation
Lymphoma Foundation of America
National Association of Social Workers
NorthShore University HealthSystem
Robert H. Lurie Comprehensive Cancer Center of
Northwestern University
Susan G. Komen for the Cure

PUBLIC PARTNERS

The Leukemia & Lymphoma Society

Centers for Disease Control and Prevention
Health Resources and Services Administration
National Cancer Institute
National Institute of General Medical Sciences
Office of Smoking and Health
Office of the Assistant Secretary for Health (Office of
Minority Health and DHHS)
The University of Texas MD Anderson Cancer Center



Empowering Communities in the Era of Health Care Reform

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Mary E. Gonzalez

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Mentor/Mentee Event

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Consultants

Denise Bates Patricia Fuchs, RD Genma Holmes

Symposium General Information

PUBLICATIONS

The Symposium proceedings may be published in an appropriate medical or scientific journal. The Intercultural Cancer Council will publish a separate document focusing on findings and recommendations resulting from the Symposium.

Audio or videotaping is prohibited without written permission from the Course Directors.

DISCLOSURE STATEMENT OF RELATIONSHIP

It is our policy that health providers, faculty and other speakers disclose the existence of any significant financial or other relationships with companies whose products or services may be discussed in the activity; e. g. research grant support, consultancies. Specific disclosures will be made to the participants prior to the educational activity.

Speakers, topics, program schedule, and credit hours are subject to change.

SYMPOSIUM GENERAL INFORMATION NAME BADGES

Name badges MUST be worn at all times for admission to the Marketplace of Ideas, meetings, all meal functions, receptions, the poster picnic and the banquet.

NON-REGISTERED PARTICIPANT MEALS

All meals and receptions are included as part of the registration fee. If you are bringing a guest to a meal function, please purchase guest tickets at the Symposium Registration Center at least 24 hours in advance of the function. Guest badges will be issued and must be worn to the meal function to obtain service. Ticket prices are as follows:

All Breakfasts \$35.00/day/person All Luncheons \$50.00/day/person

HEIGHT & HOPE AWARDS RECEPTION AND CELEBRATION

Friday, June 29 \$50.00/person online before June 23; \$100.00/person onsite

GREAT AMERICAN POSTER PICNIC – LUNCH-TIME EVENT

Saturday, June 30 \$50.00/person

LASALLE D. LEFFALL, JR. AWARDS RECEPTION & BANQUET

Saturday, June 30 \$75.00/person online before June 23;

\$150.00/person

CLOSING SESSION BRUNCH

Sunday, July 1 \$50.00/person

REGISTRATION CENTER

Grand Ballroom Prefunction Area Level Four (4) Hilton Americas - Houston Hotel 1600 Lamar

Houston, Texas, 77010 USA Phone: 1-713-739-8000

SYMPOSIUM REGISTRATION DESK

Hours of Operation:

Tuesday, June 26
 Wednesday, June 27
 Thursday, June 28
 Friday, June 29
 Saturday, June 30
 Sunday, July 1
 2:00 pm - 6:00 pm
 7:00 am - 8:30 pm
 7:00 am - 5:00 pm
 7:00 am - 5:00 pm
 7:00 am - 11:00 am

The Message Center is located near the Registration Desk on the Grand Ballroom Level, Fourth Floor.

The hotel concierge desk (in the main lobby) is staffed during peak hours to assist Symposium participants.

GREAT AMERICAN POSTER PICNIC

Posters must be set-up on Saturday, June 30, 2012, between 10:00 AM and 11:45 AM in the Grand Ballroom A-F. All posters must:

- 1. Fit in a 4 ft. x 8 ft. dimension
- 2. Be secured with velcro (PUSH PINS CANNOT BE USED)
- 3. Possess a clear and concise title
- 4. Have correct grammar and spelling
- Be neat and attractive in appearance such as color coordination and borders

You must be present during your poster presentation that begins at 12:15 PM and lasts until 2:00 PM. Please remove your posters immediately at the conclusion of your presentation. Any materials remaining on the poster boards will be discarded. You must provide your own Velcro; no push pins. If you need assistance, please check in with the Symposium Registration Desk.

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All press must obtain a badge at the Symposium Registration Desk on the Grand Ballroom Level, Fourth Floor.

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Thank you for not smoking in any of the meeting rooms, meeting room foyers, meal functions, or registration areas.

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Tuesday-Wednesday, June 26-27



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

Pre-Symposium Meetings

TUESDAY, JUNE 26, 2012

4:00 PM - 6:00 PM Intercultural Cancer Council (ICC) National Network Leaders Business Meeting

Meeting Room 340 A

6:00 PM - 7:00 PM Intercultural Cancer Council (ICC) National Network Leaders and Interim

Governing Board Dinner *Meeting Room 340 B*

7:00 PM – 10:00 PM Intercultural Cancer Council (ICC) Interim Governing Board Meeting

Meeting Room 340A

WEDNESDAY, JUNE 27, 2012

8:00 AM – 1:00 PM The Asian and Pacific Islander National Cancer Survivors Network (APINCSN) National

Advisory Council Meeting

Meeting Room 340B

9:00 AM – 1:00 PM Intercultural Cancer Council (ICC) National Network Leaders Business Meeting

Meeting Room 340A

Wednesday, June 27



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

Professional Only Program

WEDNESDAY, JUNE 27, 2012

7:00 AM – 8:00 AM **REGISTRATION**

7:00 AM – 8:00 AM Continental Breakfast

Grand Ballroom Pre Function K,L

1:30 PM - 5:00 PM **OPENING CEREMONY**

Grand Ballroom A-F

Taiko Drummers

Chanter

COLOR GUARD

NATIONAL ANTHEM

INVOCATION

Jose Cedillo, Manager, Chaplaincy and Pastoral Education, The University of Texas MD Anderson Cancer Center

OPENING REMARKS

SETTING THE STAGE

Dileep G. Bal, MD, MS, MPH, Intercultural Cancer Council Chair

Honorary Chairs:

Charles A. LeMaistre, MD, Former President, The University of Texas MD Anderson Cancer Center and Former Chancellor, The University of Texas

Pamela M. Jackson, MS, Interim Executive Director, Intercultural Cancer Council **Betty Lee Hawks, MA,** Former Special Assistant to the Director, Office of Minority Health, Department of Health and Human Services; APPEAL Board Chair

Harold P. Freeman, MD, President and Founder, Ralph Lauren Center for Cancer Care and Prevention, Senior Advisor to Director of the National Cancer Institute

WELCOME FROM PUBLIC OFFICIALS

The Honorable Sheila Jackson Lee, 18th Congressional District Mayor Pro Tem Ed Gonzalez, City of Houston

SURVIVOR'S PROMENADE

Grand Marshall: Venus Ginés, MA P/CHWI, CEO/Founder, Día de la Mujer Latina™ Inc

MUSICAL SELECTION

REFLECTION PERIOD

COL (Ret.) James E. Williams, Jr., MS, SPHR, ICC Immediate Past Chair

Honoring the ICC Board Members who have passed away

Wednesday-Thursday, June 27-28



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

REMARKS ON BEHALF OF THE SURVIVORS

"Quo vadis ICC: Past, Present Future"

Marjorie Kagawa-Singer, PhD, MA, MN, RN, FAAN, Faculty Associate, UCLA Center for Health Policy Research, Professor, UCLA School of Public Health and Department of Asian American Studies

5:00 PM – 6:00 PM **OPENING KEYNOTE**

Grand Ballroom A-F

S. Leonard Syme, PhD, Professor of Epidemiology and Community Health. University of

California at Berkeley

6:00 PM – 6:30PM **BREAK**

6:30 PM – 8:30 PM FOUNDER'S AWARD RECEPTION

Grand Ballroom H,I,K,L

This award in presented to individual(s) living a personal and professional life that speaks to the reason the Founders created the ICC and who are contributing to its mission. This session will also recognize the First Ladies of the ICC for their tremendous support, outstanding commitment, passion and leadership contributions to the Intercultural Cancer Council over the past 25 years.

Honoree:

Sandral Hullett, MD, MPH, CEO & Medical Director, Cooper Green Hospital

THURSDAY, JUNE 28, 2012

6:00 AM – 7:00 AM "EXERCISE YOUR WAY TO GOOD HEALTH"

 $Awake\ with\ the\ rising\ sun\ and\ jump-start\ your\ day\ by\ participating\ in\ a\ refreshing\ exercise$

program. Get energized, rejuvenated and ready for another exciting day!

7:00 AM – 8:00 PM **CONTINENTAL BREAKFAST**

7:00 AM – 5:00 PM **REGISTRATION**

7:45 AM – 8:00 AM **SETTING THE STAGE FOR THE DAY**

Grand Ballroom B,C,E,F

Lovell A. Jones, PhD, Director and Professor, Center for Health Equity & Evaluation Research,

The University of Texas MD Anderson Cancer Center/University of Houston

 $8:00~\mathrm{AM}-11:45~\mathrm{AM} \qquad \qquad \text{``Mapping the Future of Science and Service Towards Health Equity in the Era of Health}$

Reform"

Grand Ballroom B,C,E,F

This exciting facilitated panel will feature leaders of key agencies and organizations working to reduce health disparities. Among the issues to be discussed will be challenges and successes in health disparities research, effective translation to communities and community based programs and necessary system changes to make meaningful and measurable reductions in health

disparities.

Thursday, June 28



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

8:00 AM - 8:10 AM

SESSION OVERVIEW

Moderator:

Tom Kean, MPH, President and CEO, C-Change

8:10 AM - 8:50 AM

SETTING THE STAGE

The Evolution of Science and Service in Health Equity

William (Bill) C. Jenkins, MPH, PhD, Disease Transmission Specialist, Former Supervisory Epidemiologist, National Center for HIV, STD, and TB Prevention, Centers for Disease Control and Prevention, US Department of Health and Human Services (HHS)

Current Status of Science and Service in Health Equity

Maureen Lichtveld, MD, MPH

Freeport McMoRan Chair of Environmental Policy Department of Environmental Health Sciences Tulane University School of Public Health and Tropical Medicine

REACTOR PANEL

9:00 AM - 10:00 AM

Panel 1: Mapping The Future of Science Towards Health Equity

Topics include:

- · Critical research questions going forward
- Research questions necessary to find solutions
- Health services research
- · The research workforce
- Innovative research enterprises
- Moving research results into action faster

Panelists:

- Amelie G. Ramirez, DrPH, Director, Institute for Health Promotions Research, University of Texas Health Science Center, San Antonio
- Kathy Ko, President and CEO, Asian & Pacific Islander American Health Forum
- Roger Bulger, MD, President and CEO (retired), Association of Academic Health Centers
- Allen S. Lichter, MD, CEO, American Society for Clinical Oncology
- **Jeffrey A. Henderson, MD, MPH,** President & CEO, Black Hills Center for American Indian Health, Cheyenne River Sioux Tribe
- Ahmed Calvo, MD, MPH, Senior Medical Officer, Office of Health Information and Technology and Quality, US Department of Health Resources and Services Administration (HHS)
- Raymond DuBois, MD, PhD, Executive Vice President, The University of Texas MD Anderson Cancer Center

9:55 AM – 10:15 AM

NETWORKING BREAK & LIGHT SNACK

Pre Function Area

10:15 AM - 11:20 AM

Panel 2: Mapping the Future of Service Towards Health Equity

Topics include:

- New service delivery models and their potential impact
- The next generation public health agenda
- Major policy drivers
- How to scale up from demonstration projects
- Innovative service programs
- The service workforce



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

Panelists:

- Eduardo Sanchez, MD, MPH, Vice-President & CMO, Blue Cross/Blue Shield of Texas
- Wayne S. Rawlins, MD, MBA, National Medical Director, Racial and Ethnic Equality Initiatives, Aetna
- Richard Murray, MD, Vice President, Global Center for Scientific Affairs, Merck & Co., Inc.
- Gary Earl, BA, Vice President for Health Transformation, United Healthcare
- J. Nadine Gracia, MD, MSCE, Deputy Assistant Secretary of Minority Health (Acting), Acting Director of the Office of Minority Health (OMH), US Department of Health and Human Services (HHS)
- Nancy C. Lee, MD, Deputy Assistant Secretary for Health-Women's Health, Director of the Office on Women's Health (OWH), US Department of Health and Human Services (HHS)
- Christina Austin-Valere, PhD, LCSW, Advocacy Director, Board of Directors, American Society
 of Social Work

11:40 AM - 11:45 AM

SESSION CLOSING

Tom Kean, MPH, President and CEO, C-Change

11:45 AM - 12:00 PM

BREAK

12:00 PM - 1:45 PM

SUSAN MATSUKO SHINAGAWA LIVESTRONG CANCER CONTROL LEADERSHIP AWARD LUNCHEON

Grand Ballroom H,I,K,L

Presentation of an award to an individual or group whose demonstrated leadership in the area of cancer control goes beyond the expected to the exceptional, through the formulation and execution of policies, programs, partnerships and/or research to eliminate the unequal burden of cancer among racial and ethnic minorities and medically underserved populations.

Speaker:

Robert G. Robinson, MSW, DrPH, Health Power Editor, Smoking and Health, and Race, Culture and Health

Honorees:

COL (Ret.) James E. Williams, Jr., MS, SPHR, ICC Immediate Past Chair
Olga G. Sanchez, Community Health Program Representative, Moores Cancer

Olga G. Sanchez, Community Health Program Representative, Moores Cancer Center, University of California, San Diego

1:45 PM - 2:00 PM

BREAK

2:00 PM - 3:00PM

MARKETPLACE OF IDEAS: "MAKING CONNECTIONS TO REDUCE HEALTH INEQUITIES" Grand Ballroom B.C.E.F

The Marketplace of Ideas symbolizes our effort to create an exciting and informative conference that will stimulate the exchange of ideas, information and resources. The Marketplace will enable all to gather valuable tools for the communities we serve, including the promotion of cancer awareness, screening, treatment, quality of life and health equity in the minority and the medically underserved. Sponsored by ICC Regional Network Leaders, the Marketplace of Ideas is a special networking event designed to help attendees learn about resources available from Resource Providers from local, state, national, federal, non-profit, and for-profit agencies and organizations. Through this event, Community-Based Organizations (CBOs) can connect with national, state and local partners to chart a new course together. Partners and CBOs can identify specific ways to work together to eliminate health disparities and health inequities at the local level.

Thursday-Friday, June 28-29



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

3:30 PM - 5:00 PM

The Marriage Test - A play about colorectal cancer

Grand Ballroom B,C,E,F

The Marriage Test was produced to educate the public about colorectal cancer in an entertaining and humorous way, while at the same time informing individuals about the importance of early screening and detection. It is about one family's emotional reactions in learning that loved ones had been diagnosed with the disease. The play reveals how they react to this life-altering news and how they deal with the choices they must make about their lives and health with strength, humor, and wisdom. The playwright, Thomas Meloncon, is a native Houstonian nationally known for his many plays and three books of poetry. He has been honored with numerous awards, including a Bronze Medallion from the City of Houston for his off-Broadway debut of The Diary of a Black Man. Mr. Meloncon has produced a variety of works for the American Cancer Society, the Houston Area Women's Shelter, the Susan G. Komen Breast Cancer Foundation, the African American Healthy Marriage Initiative, and The University of Texas Medical Branch at Galveston. The presentation of The Marriage Test at this Symposium is sponsored jointly by the Dan Duncan Cancer Center at Baylor College of Medicine and the American Cancer Society.

5:00 PM - 6:30PM

Continuation OF MARKETPLACE OF IDEAS: "MAKING CONNECTIONS TO REDUCE HEALTH INEOUITIES"

Grand Ballroom A-C

FRIDAY, JUNE 29, 2012

6:00 AM - 7:00 AM

"EXERCISE YOUR WAY TO GOOD HEALTH"

Awake with the rising sun and jump-start your day by participating in a refreshing exercise program. Get energized, rejuvenated and ready for another exciting day!

7:00 AM – 5:00 PM

REGISTRATION

7:00 AM - 8:00 AM

CONTINENTAL BREAKFAST

Grand Ballroom Pre Function Area AD

8:00 AM - 8:15 AM

SETTING THE STAGE FOR THE DAY

Grand Ballroom B,C,E,F

COL (Ret.) James E. Williams, Jr., MS, SPHR, ICC Immediate Past Chair

8:15 AM - 11:45 AM

CHARTING NEW INITIATIVES IN HEALTH DISPARITIES – OVERVIEW

Grand Ballroom B,C,E,F

A panel of community individuals and/or organizations from previous HOPE (Helping Other People Endure) Award winners will share best practices in mobilizing communities to address health disparities, whether through programs and/or policy development and implementation. In follow-up to this panel, leaders from key federal agencies will present new initiatives (intra- and interagency) to address health disparities. They will also provide comment on HOPE/Community initiatives and how the community perspective might influence future RFA development, provision of technical assistance and capacity building and other programmatic areas. Time will be allotted for facilitated discussion with the larger audience.

Chair:

Nancy C. Lee, MD, Deputy Assistant Secretary for Health-Women's Health, Director of the Office on Women's Health (OWH), US Department of Health and Human Services (HHS)

Friday, June 29



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

Panel 1: HOPE Awardees

Lawrence W. McRae, President/CEO, McRae Prostate Cancer Awareness Foundation

Venus Ginés, MA, P/CHWI CEO/Founder, Día de la Mujer Latina™ Inc

Celeste (CeCe) Whitewolf, JD, Native People's Circle of Hope

Victor Kaiwi Pang, President, Pacific Islander Health Partnerships

Ann Duesing, Board Member, Mountain Empire Older Citizens, Inc / Mountain Laurel Cancer

Resource and Support Center

Panel 2: Federal agency representatives

Ahmed Calvo, MD, MPH, Senior Medical Officer, Office of Health Information and Technology and Quality, US Department of Health Resources and Services Administration (HHS)

Lumbe Davis, MPH, Program Officer, Comprehensive Cancer Control Program, Centers for Disease Control and Prevention, DHHS

Nancy Lee, MD, Deputy Assistant Secretary for Health-Women's Health, Director of the Office on Women's Health (OWH), US Department of Health and Human Services (HHS)

Short break

Discussants:

Harold P. Freeman, MD, President and Founder, Ralph Lauren Center for Cancer Care and Prevention, Senior Advisor to Director of the National Cancer Institute

Tasha Tilghman-Bryant, MPA, Manager, Strategic Initiatives, C-Change – Collaborating to Conquer Cancer

Facilitated questions and answers from the audience

11:45 AM - 12:00PM **BREAK**

12:00 PM - 1:45 PM HERBERT W. NICKENS MEMORIAL LECTURESHIP LUNCHEON

Grand Ballroom H,I,K,L

Speaker & Honoree: David Satcher, MD, PhD

Director, The Satcher Health Leadership Institute and Center of Excellence on Health Disparities

Poussaint-Satcher-Cosby Chair in Mental Health, Morehouse School of Medicine

16th Surgeon General of the United States

1:45 PM – 2:00 PM **BREAK**

2:00 PM - 5:00 PM PROFESSIONAL AND STUDENT ORAL PRESENTATIONS

Third Floor Meeting Rooms

2:00 PM – 5:00 PM ICC NETWORK REGIONAL LEADERS FORUM

RESOURCES, TOOLS (TOOLKITS) AND STRATEGIES TO REDUCE HEALTH INEQUITIES

Grand Ballroom A,D

2:00 PM – 3:20 PM DISASTER PREPAREDNESS: COMMUNITY EMPOWERMENT

COMMUNITY DISASTER ALLIANCE OF NASHVILLE (CDAN)

Grand Ballroom A,D

The CDAN and its partners provide work with vulnerable populations in Nashville/Davidson County to empower them to work effectively toward being self-reliant before, during and after a

Friday, June 29



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

disaster. CDAN provides educational opportunities in the area of disaster preparedness through trainings, seminars, workshops and distribution of literature and other materials.

3:30 PM - 5:00 PM

PATIENT NAVIGATION

Grand Ballroom C,F

Harold P. Freeman, MD, President and Founder, Ralph Lauren Center for Cancer Care and Prevention, Senior Advisor to Director of the National Cancer Institute

This session will discuss successes, barriers and key components necessary to implement and sustain patient navigation programs.

2:00 PM - 5:00 PM

CLINICAL TRIALS IN CHRONIC DISEASE FORUM

Grand Ballroom B,E

Facilitator

James H. Powell, MD, CPI, Principal Investigator, Project I.M.P.A.C.T. (Increase Minority Awareness and Participation in Clinical Trials), a Program of the National Medical Association

Recorder: Jane Daye, MA, Program Manager, Pacific Center of Excellence in the Elimination of Disparities, Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of Hawaii

By experiencing what we have learned from past experiences, the panelists and participants in this session will discuss the critical need to improve collaboration between communities, clinicians and academicians in order to increase participation of minority and medically underserved populations in clinical research.

2:00 PM - 5:00 PM

NATIONAL PARTNERSHIP FOR ACTION: REGIONAL HEALTH EQUITY COUNCILS $Grand\ Ballroom\ A.D$

Speaker: Rochelle Rollins, PhD, MPH, Director, Division of Policy and Data, Office of Minority Health, US HHS and Chair, Federal Interagency Health Equity Team, National Partnership for Action

The National Partnership for Action (NPA) to end health disparities is a public-private initiative that seeks to mobilize a nationwide, comprehensive, community-driven, and sustained approach to combating health disparities and to move the nation toward achieving health equity. Regional Health Equity Councils (RHEC) serve as leaders and catalysts for strengthening health equity actions within a region in response to the NPA's National Stakeholder Strategy for Achieving Health Equity.

6:00 PM - 9:00 PM

HEIGHT AND HOPE AWARDS CELEBRATION

Grand Ballroom G-L

LET'S CELEBRATE! The Height and HOPE (Helping Other People Endure) Awards will be announced and presented during a rousing reception and celebration featuring multi-cultural foods and entertainment. Please feel free to dress in attire representative of your cultural background.

Dorothy I. Height Honoree:

Marilyn Hughes Gaston, MD, Former Assistant Surgeon General and Director, Bureau of Primary Health Care, US Public Health Service Rear Admiral, USPHS, Ret., Co-Director, The Gaston and Porter Health Improvement Center



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

SATURDAY, JUNE 30, 2012

6:00 AM - 7:00 AM

"EXERCISE YOUR WAY TO GOOD HEALTH"

Awake with the rising sun and jump-start your day by participating in a refreshing exercise program. Get energized, rejuvenated and ready for another exciting day

7:00 AM - 5:00 PM

REGISTRATION

7:00 AM - 8:30 AM

BREAKFAST SESSION - HAROLD P. FREEMAN LECTURESHIP

Grand Ballroom H,I,K,L

Chair:

Harold P. Freeman, MD, President and Founder, Ralph Lauren Center for Cancer Care and Prevention, Senior Advisor to Director of the National Cancer Institute

Speaker & Honoree:

Billy U. Philips, Jr., PhD, MHA, Vice President for Rural and Community Health, Texas Tech University Health Sciences Center

8:30 AM - 8:45 AM

SETTING THE STAGE FOR THE DAY

Lee Buenconsejo-Lum, MD, FAAFP, Program Chair, 25th Anniversary of the Biennial Symposium on Minorities, the Medically Underserved and Health Equity; Associate Professor, Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of Hawaii

8:45 AM - 10:15 AM

CHRONIC DISEASE PREVENTION AND CONTROL

Grand Ballroom H,I,K,L

Social Justice Concerns in Stemming the Tobacco, Diabetes and Obesity Epidemics in the Era of Obama Care

Chair:

Amber E. Bullock, MPH, CHES, Executive Vice President, Program Development, LEGACY

Sponsored by Legacy, this panel will highlight the life-saving role of preventing and controlling risk factors for chronic disease and cancer: tobacco prevention and control, community-based strategies for addressing poor diet, lack of physical activity and addressing the social determinants of health. The panelists will discuss efforts and needed strategies to ensure that chronic disease prevention becomes a sustainable reality for communities of color with health care reform, while keeping social justice issues front and center for prevention work.

- "Health and Place Matters Social Determinants for Prevention"
 Marjorie A. Paloma, MPH, Senior Policy Advisor, RWJF Health Group
- "Hope & Audacity: Social Justice Prevention Perspective"
 Makani Themba-Nixon, Executive Director, Praxis Project
- "Mobilizing local, National and International Resources to Address Needs in Resource Limited Settings: A Reality Check"

Neal A. Palafox, MD, MPH, Principal Investigator, Pacific Center of Excellence in the Elimination of Disparities, Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of Hawaii

• "Strategies to Sustain the Tobacco Control Movement: Impact on Communities of Color"

Kevin Collins, PhD, Deputy Branch Chief (Acting), Epidemiology Branch, Office of Smoking and Health, Centers for Disease Control and Prevention (CDC), US Department of Health and Human Services (HHS)



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

Discussant:

Dileep G. Bal, MD, MS, MPH, ICC Chair

Facilitated Discussion

SHORT BREAK

10:30 AM -12:00 PM

Continuation of Chronic Disease Prevention and Control Panel

- "Tobacco Related Disparities: Menthol Wars"
 - **Phillip Gardiner, DrPH**, Social and Behavioral Sciences and Neurosciences and Nicotine Dependence Research Administrator for the Tobacco Related Disease Research Program (TRDRP), University of California Office of the President
- "The Obesity Epidemic Utilizing Lessons from the Tobacco Control Movement & Pearls of Wisdom From the Obesity Forefronts"
 Rod Lew, MPH, Executive Director, Asian Pacific Partners for Empowerment Advocacy and Leadership (APPEAL)
- "Diabetes Prevention and Management Among Pacific Islanders"
 Nia Aitaoto, MPH, MS, PhD(c), Principal Investigator, Faith in Action Research Alliance
- "Controlling Chronic Disease in Indigenous Populations"
 Linda Burhansstipanov, MSPH, DrPH, (Cherokee Nation of Oklahoma), Founder/President Native American Cancer Research

FACILITATED DISCUSSION

12:15 PM - 2:00 PM

THE GREAT AMERICAN POSTER PICNIC

Grand Ballroom A,B,D,E

Professional, community and student poster presentations depicting research projects set in a relaxed, traditional all-American picnic environment.

2:00 PM - 3:15 PM

THE FUTURE OF THE AFFORDABLE CARE ACT AT THE FEDERAL AND STATE LEVELS

Meeting Room 335 A

This session will provide participants an in-depth insight of where we are now and a glimpse of where we will be in the future with regard to the proposed health care act. Participants will receive the most current information about the affordable healthcare act and how it will affect them individually. Topics will include the underinsured, disparity issues and access to care.

Jennie R. Cook, President, ICC Caucus, Past Chairman, National Board of Directora, American Cancer Society

Citseko Staples Miller, Senior Specialist, State and Local Campaigns, American Cancer Society Cancer Action Network, Inc.

3:30 PM - 4:45 PM

SOCIAL JUSTICE: RE-LIGHTING THE FIRE

 $Meeting\,Room\,335\,A$

Panelists in this special session will challenge participants to discuss ways to mobilize minority and medically underserved communities to be effective advocates for change.

Dileep G. Bal, MD, MS, MPH, ICC Chair

Recorder: Mavis Nitta, MPH, CHES, Legacy Project Coordinator, Pacific Center of Excellence in the Elimination of Disparities, Department of Family Medicine and Community Health, University of Hawaii



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

2:00 PM - 4:45 PM

COMMUNITY-BASED SUCCESS STORIES Breakout sessions

Participants will have the opportunity to attend breakout sessions organized around thematic areas critical to community-based efforts to reduce health disparities. Each session will include up to 3 panelists and time for a facilitated discussion about next steps and recommendations to further the system improvements required to effect meaningful change. These recommendations will be reported to the large group on Sunday morning and will be used to guide strategic priorities for the ICC and other organizations.

Breakout sessions/focus areas:

2:00 PM - 3:15 PM

BREAKOUT SESSION: ENGAGING POLICY MAKERS

Meeting Room 340B

This session will highlight community-driven efforts to engage policy makers which have resulted in policy changes that have or will impact chronic disease prevention, control and/or treatment.

Moderator: Neal A. Palafox, MD, MPH, Principal Investigator, Pacific Center of Excellence in the Elimination of Disparities, Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of Hawaii

Recorder: LaKeisha Batts, PhD, Kellogg Health Scholar Postdoctoral Fellow, Center for Health Equity & Evaluation Research, The University of Texas MD Anderson Cancer Center/University of Houston

2:00 PM - 3:15 PM

BREAKOUT SESSION: BUILDING/MAINTAINING COALITIONS - A

Meeting Room 339 A

This session will highlight successful strategies or innovative approaches used to build, rebuild or maintain active coalitions focused on control of cancer or chronic disease.

Moderator: Frankie Denise Powell, PhD, Associate Professor, School of Education, B-K Program, University of North Carolina at Pembroke

Recorder: Patricia A. Torris, MPA, Program Manager, Pacific Regional Central Cancer Registry, Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of Hawaii

2:00 PM - 3:15 PM

BREAKOUT SESSION: SCREENING-FOCUSED SUCCESSES

Meeting Room 339 B

This session will highlight community-based efforts to improve screening for chronic disease in populations with reduced rates of screening services.

Moderator: Bonnie Wheatley, MPH, MA, EdD, Vice-President, Zephyrus Group, LLC *Recorder:* Celeste (CeCe) Whitewolf, JD, Native People's Circle of Hope

2:00 PM - 3:15 PM

BREAKOUT SESSION: SURVIVORSHIP-FOCUSED SUCCESSES

Meeting Room 340 A

This session will highlight community-based efforts to improve the quality of life for persons diagnosed with cancer or late-stage chronic disease.

Moderator: Patricia K. Bradley, PhD, RN, Associate Professor, College of Nursing, Villanova University



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

Recorder: Stacy Lloyd, PhD, Kellogg Health Scholar Postdoctoral Fellow, Center for Health Equity & Evaluation Research, The University of Texas MD Anderson Cancer Center/University of Houston

3:30 PM – 4:45 PM BREAKOUT SESSION: BUILDING/MAINTAINING COALITIONS – B

Meeting Room 335 A

This session will highlight successful strategies or innovative approaches used to build, rebuild or maintain active coalitions focused on control of cancer or chronic disease.

Moderator: Neal Palafox, MD, MPH, Principal Investigator, Pacific Center of Excellence in the Elimination of Disparities, John A. Burns School of Medicine, University of Hawaii *Recorder*: Denae W. King, PhD, Assistant Professor, The University of Texas Health Science Center at Tyler

3:30 PM – 4:45 PM BREAKOUT SESSION: SOCIAL DETERMINANTS (HOUSING, POVERTY, EDUCATION)

Meeting Room 340 A

This session will highlight projects with demonstrated improvement in health outcomes, based on work primarily addressing reduction of poverty, improvements in education and/or the living environment.

Moderator: Carlos Gallego, MEd, Director of Community Partnerships,

Minnesota Children's Museum

Recorder: Frankie Denise Powell, PhD, Associate Professor, School of Education, B-K Program, University of North Carolina at Pembroke

3:30 PM – 4:45 PM BREAKOUT SESSION: PREVENTION-FOCUSED SUCCESSES

Meeting Room 339 A

This session will highlight projects resulting in improvements in risk factors for developing chronic diseases, including cancer.

Moderator: Celeste (CeCe) Whitewolf, JD, Native People's Circle of Hope *Recorder:* Bonnie Wheatley, MPH, MA, EdD, Vice-President, Zephyrus Group, LLC

3:30 PM – 4:45 PM BREAKOUT SESSION: TREATMENT / ACCESS TO TREATMENT

Meeting Room 339 B

This session will highlight projects resulting in improved treatment or access to treatment for cancer or other chronic diseases.

Moderator: Sharon Barrett, MS, DrPH(c), Founder and Principal for S.E.B. and Associates *Recorder: Kimberly Enard, PhD, RN*, Postdoctoral Fellow, The University of Texas MD Anderson Cancer Center

3:30 PM – 4:45 PM **SURVIVORSHIP MEETING**

 $Meeting\ Room\ 340B$

As cancer diagnosis and treatment have advanced, often cancer patients live for many years and have a myriad of physical and emotional issues to manage. In addition, the broad diversity of cancer survivors requires us to consider multi-cultural aspects of survivorship. This breakout session will include perspectives of researchers and community advocates regarding the issues facing diverse cancer survivors and the opportunities to address these issues.

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Saturday, June 30 - Sunday, July 1



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

Chair: Linda Fleisher, MPH, PhD(c), Assistant Vice President, Health Communications and Health Disparities, Fox Chase Cancer Center

Panelists:

Diana D. Jeffery, PhD, Director, Center for Healthcare Management Studies Health Program Analysis and Evaluation TRICARE, Management Activity Military Health System Assistant Secretary of Defense, Health Affairs

Westley Sholes, MPA, Vice President of Health Programs, National Association of Black County Officials

Patricia K. Bradley, PhD, RN, Associate Professor, College of Nursing, Villanova University **Kimlin Tam Ashing-Giwa, PhD,** Professor and Founding Director, Center of Community Alliance for Research and Education, Division of Population Sciences, City of Hope

Maria Guerra- Sanchez, RN, CCRP, Tender Drops of Love

Furjen Deng, PhD, Light and Salt

6:00 PM - 6:45 PM **RECEPTION**

Grand Ballroom G,J

7:00 PM - 9:00 PM

LASALLE D. LEFFALL, JR. AWARDS BANQUET & GALA

Grand Ballroom H,I,K,L

Recognizes individuals and organizations that have distinguished themselves in addressing the cancer crisis in minority and medically underserved communities through educational programs, clinical service, research, or public awareness.

HONOREE

Neal A. Palafox, MD, MPH

Principal Investigator, Pacific Center of Excellence in the Elimination of Disparities Department of Family Medicine and Community Health John A. Burns School of Medicine, University of Hawaii

LEAP OF FAITH AWARD

The Leap of Faith award recognizes an organization and/or individual who has come forward at critical moments to support the mission, ideas and efforts of the Biennial Symposium Series and/or the Intercultural Cancer Council.

Honoree

University of Houston, accepting on behalf of the university **John Antel, PhD,** Provost and Senior Vice President

SUNDAY, JULY 1, 2012

6:00 AM – 7:00 AM "EXERCISE YOUR WAY TO GOOD HEALTH"

Awake with the rising sun and jump-start your day by participating in a refreshing exercise program. Get energized, rejuvenated and ready for another exciting day!

7:30 AM - 9:00 AM CONTINENTAL BREAKFAST

7:45 AM – 8:00 AM **SETTING THE STAGE FOR THE DAY**

Grand Ballroom H,I,K,L

Lovell A. Jones PhD, Director and Professor, Center for Health Equity & Evaluation Research, The University of Texas MD Anderson Cancer Center/University of Houston



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

8:00 AM - 9:45 AM

CAPACITY BUILDING WORKSHOPS

Participants will be able to select one of several concurrent workshops designed to transmit information and/or skills that can be utilized in community-based work aimed at reducing health inequity.

8:00 AM - 9:45 AM

WORKSHOP: ESTABLISHING, IMPLEMENTING AND MAINTAINING AN ACADEMIC-COMMUNITY PARTNERSHIP: ETHICAL CONSIDERATIONS

Meeting Room 336 A&B

Chair: Jean Ford, MD, Director, Johns Hopkins Center to Reduce Cancer Disparities

Contemporary IRB guidelines address key ethical principles in the protection of individual research participants, including autonomy, beneficence, nonmaleficence and justice. However, the guidelines are relatively under-developed when it comes to protecting communities engaged in community-based participatory research (CBPR) against potential adverse consequences of that research. This workshop will explore ethical challenges in CBPR, and discuss potential solutions from the perspectives of community-engaged researchers and academically-engaged community members.

Presenters:

Chanita Hughes Halbert, PhD, Professor, Department of Psychiatry and Behavioral Sciences, Medical University of South Carolina

Bettina Drake, PhD, Assistant Professor, Division of Public Health Sciences, Dept. of Surgery, Siteman Cancer Center, Washington University School of Medicine

Michele Towson, JD, Director of Grant Development, Baltimore Community College

8:00 AM - 9:45 AM

WORKSHOP: APPROACHES TO GRANT WRITING

Meeting Room 338

This workshop will review the basics of writing grant proposals and getting them funded. Topics will include needs assessment, project development, budgeting, finding funders, and general "grantsmanship" skills. The focus includes both community-based organizations and academic researchers interested in research as well as "practical" demonstration projects. Participants will also receive an extensive list of resources for additional background and continued networking after the workshop.

Presenter: Larry Laufman, EdD, Assistant Professor, Baylor College of Medicine,

8:00 AM - 9:45 AM

WORKSHOP: COLLABORATION TO ADDRESS CHRONIC DISEASES

Meeting Room 337 A

This workshop will share strategies, tips and tools useful to community coalitions working to address chronic diseases. The presenter will share specific approaches to working with chronic disease partners to achieve common goals, tips and tools for collaborative planning, sharing data, and coordinating work among common partners and populations.

Presenter: Karin Hohman, RN, MPH, President, Strategic Health Concepts

8:00 AM - 9:45 AM

WORKSHOP: ADVOCACY 101

Meeting Room 327

This workshop will explore the basics of how to be an advocate and how important this work can be. This workshop will cover the very basics but will help participants understand how important they can be to further good health at the local, state and federal levels.



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

Presenters:

Jennie Cook and Citseko Staples Miller, American Cancer Society Cancer Action Network (CAN) Jackie Young, PhD, Chief Staff Officer, High Plains Division, Hawaii Pacific, American Cancer Society, Inc. American Cancer Society, Inc.

8:00 AM - 9:45 AM

WORKSHOP: MEDIA ADVOCACY

Meeting Room 328

The Media Advocacy workshop will help advocates learn to engage the news media strategically. Whether the goal is increasing funding and support for community-based programs or advocating for more linguistically and culturally-appropriate access to health services, participants can harness the power of the news media to amplify their voices, reach policy-makers, and advance their policy goals.

Presenters: **Trish Quema, Roxanna Bautista, MPH** and **Pedro Arista,** Asian & Pacific Islanders American Health Forum (APIAHF)

8:00 AM - 9:45 AM

WORKSHOP: PROJECT SECURE: DISASTER PREPAREDNESS

Meeting Room 329

This workshop will feature community-based applications of selected findings from the SECURE RESEARCH CONSORTIUM in the context of Health Reform. The overall goal of the workshop is to examine the relationship between health reform and disaster management and the impact on at-risk communities. Presenters will focus on four interdependent questions: (1) What is the anticipated impact of Health Reform on disaster recovery in Gulf Coast communities? (2) How can we use available health data to predict the need for health services for those with a chronic disease burden during and after a disaster? (3) What are examples of evidence-based practice to strengthen community preparedness? and (4) How can schools play a role in advancing family readiness?

Presenters:

Patricia Matthews-Juarez, PhD, Associate Vice President, Faculty Affairs and Development, Professor Family and Community Medicine, Meharry Medical College

Maureen Lichtveld, MD, MPH, Freeport McMoRan Chair of Environmental Policy, Department of Environmental Health Sciences, Tulane University School of Public Health and Tropical Medicine

Alexandra (Lexi) B. Nolen, PhD, MPH, Director of Health Policy and Planning, Center to Eliminate Health Disparities, Associate Director, UTMB PAHO/WHO Collaborating Center for Training in International Health, Assistant Professor, Department of Family Medicine, The University of Texas Medical Branch Galveston

John Prochaska, DrPH, MPH, Program Manager, Assistant Professor, UTMB's Dept of Preventive Medicine and Community Health (PMCH), University of Texas Medical Branch Galveston

Faith Foreman, PhD, Assistant Director City of Houston, Dept. of Health and Human Services

8:00 AM - 9:45 AM

WORKSHOP: COMPREHENSIVE CANCER CONTROL COALITION EFFORTS TO ENGAGE DIVERSE COMMUNITY PARTNERS

Meeting Room 330

Comprehensive cancer control succeeds when communities and coalitions work together to address common cancer issues. This session will identify ways to bring together community partners and cancer coalitions to engage in collaborative efforts. We will share successful approaches to common challenges such as shared decision making, identifying resources and managing implementation.

Presenter: Leslie Given, MPA, Vice President, Strategic Health Concepts



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

8:00 AM - 9:45 AM

WORKSHOP: WHAT ARE CANCER CLINICAL TRIALS AND WHY SHOULD COMMUNITIES CARE?

Meeting Room 332

This workshop is designed to introduce the topic of cancer clinical trials to community members and cover key facts about how trials work and why they are important in advancing progress in cancer care. The workshop will address many of the common myths and misconceptions about cancer clinical trials and discuss ways to find out more about studies available in local communities.

Presenter: Margo Michaels, MPH, Executive Director, Education Network to Advance Cancer Clinical Trials (ENACCT)

8:00 AM - 9:45 AM

WORKSHOP: MAKING DATA TALK: COMMUNICATING PUBLIC HEALTH DATA Meeting Room 333

Programs need to present data to make the cancer control case to the public, media, and policy makers. However, communicating data and other scientific information to lay audiences can be difficult. It is critical to understand the totality of communication processes in public health, the many factors that influence it, and the importance of data selection and presentation. This workshop reviews communication concepts, provides recommendations on selecting and presenting data, and introduces an easy to understand framework for communicating data. Participants will receive a workbook that will be used during the workshop that will help reinforce key concepts and provide examples.

Presenter: Harry Kwon, PhD, MPH, MCHES, Office of Communications and Education National Cancer Institute (NCI)

8:00 AM - 9:45 AM

WORKSHOP: INTRODUCTION OF ONLINE CONTINUING EDUCATION PROGRAM, "ACCESS TO CANCER CARE FOR LOW-INCOME AND UNINSURED PATIENTS" Meeting Room 339 A

This workshop will focus on the impact and care issues of health disparities that exist in underserved populations in Texas and resources that are available in obtaining quality healthcare services for those populations.

Presenter: Lewis Foxhall, MD, Office of Health Policy, The University of Texas MD Anderson Cancer Center

8:00 AM - 9:45 AM

WORKSHOP: TRANSLATING EVIDENCE INTO PRACTICE: USING WHAT WORKS Meeting Room $339\,B$

Many grants require applicants to use "evidence-based" programs. What does that mean and how do you do it? In this session, we will briefly cover levels of evidence and where to find evidence-based programs and strategies. We will spend the majority of the session discussing how to select strategies to fit an organization and its project objectives. We'll put these planning steps into practice through small group exercises.

Presenters: Maria Fernandez, PhD, Associate Professor of Health Promotion and Behavioral Sciences, The University of Texas School of Public Health

Linda Civallero, MPH, Center for Community-Engaged Translational Research, The University of Texas MD Anderson Cancer Center

8:00 AM - 9:45 AM

WORKSHOP: USE OF SOCIAL MEDIA TO DO COMMUNITY WORK Meeting Room 340 A

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BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

This workshop will examine how the use of social medial platforms, like Facebook, Twitter, and blogging can be used to educate, empower, and bring positive changes to communities.

Presenters:

Genma Holmes, Radio Host, Living Your Best Life Now

Shawn P. Williams, Publisher and Editor-in-Chief, Dallas South News

Jody Schoger, Columnist, OncologyTimes, Co-Founder, "BreastCancerSocialMedia"

8:00 AM - 9:45 AM

WORKSHOP: USING MULTI-SECTOR COLLABORATION TO ADDRESS DISPARITIES ACROSS THE CONTINUUM OF CANCER RESEARCH, PREVENTION AND CARE Meeting Room 340 B

Participants at this workshop will be provided with an overview of C-Change's multi-sector approach to its six strategic initiatives – Patient Privacy & Cancer Research (HIPAA), Cancer Risk Reduction, Cancer Health Disparities, Cancer Workforce, Value in Cancer Care, and Comprehensive Cancer Control. Each initiative incorporates aspects of cancer health disparities, vulnerable communities, and/or underrepresented professionals. A panel of C-Change members will outline strategies employed, highlight available materials and tools developed by C-Change, and describe how these resources can be used to establish similar cancer control initiatives in communities throughout the country.

Presenters:

Tasha Tilghman-Bryant, MPA, Manager, Stategic Initiatives, C-Change **Maureen Lichtveld, MD, MPH,** Freeport McMoRan Chair of Environmental Policy, Department of Environmental Health Sciences, Tulane University School of Public Health and Tropical Medicine

9:45: AM – 10:00 AM **BREAK**

Prefunction Grand Ballroom G

10:00 AM – 11:15 AM **PLENARY SESSION**

Grand Ballroom H,I,K,L

10:00 AM – 10:45 AM **VOICES**

VOICES FROM THE COMMUNITY:

Report out from the community breakout sessions on priority areas

Lee Buenconsejo-Lum MD, FAAFP, Program Chair, 25th Anniversary of the Biennial Symposium on Minorities, the Medically Underserved and Health Equity, Associate Professor, Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of Hawaii

10:45 AM – 11:15 AM **REFLECTIONS AND NEXT STEPS**:

Honorary Chairs:

Charles A. LeMaistre, MD, Former President, The University of Texas MD Anderson Cancer Center and Former Chancellor, The University of Texas

Pamela M. Jackson, MS, Interim Executive Director, Intercultural Cancer Council **Betty Lee Hawks, MA,** Former Special Assistant to the Director, Office of Minority Health,

Department of Health and Human Services; APPEAL Board Chair

Harold P. Freeman, MD, President and Founder, Ralph Lauren Center for Cancer Care and Prevention, Senior Advisor to Director of the National Cancer Institute

Dileep G. Bal, MD, MS, MPH, ICC Chair

11:15 AM – 11:30 AM **BREAK**

11:30 AM – 1:00 PM FAREWELL JAZZ BRUNCH - MAJOR KEYNOTE SPEAKER

Grand Ballroom H,I,K,L

1:00 PM **EVALUATION AND ADJOURNMENT**

Tuesday, June 26



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

Credit Only Students Program

TUESDAY, JUNE 26, 2012

2:00 PM - 6:00 PM	REGISTRATION FOR CREDIT TRACK STUDENTS
2:30 PM – 2:45 PM	WELCOME Grand Ballroom J,K
	Lovell A. Jones PhD, Director and Professor, Center for Health Equity & Evaluation Research, The University of Texas MD Anderson Cancer Center/University of Houston
2:45 PM – 3:00 PM	WELCOME Ernest Hawk, MD, MPH, Vice President, Cancer Prevention, The University of Texas MD Anderson Cancer Center
3:00 PM – 3:15 PM	WELCOME John Antel, PhD, Provost and Senior Vice President, University of Houston
3:15 PM – 3:30 PM	WELCOME James Heggie, MS, Interim Executive Director, HDEART Consortium Leadership
3:30 PM – 3:35 PM	INTRODUCTION OF THE KEYNOTE SPEAKER
	Frank Talamantes, PhD, Professor Emeritus, University of California Santa Cruz
3:35 PM – 4:35 PM	KEYNOTE SPEAKER
	Richard Tapia, PhD, University Professor, Department of Computational and Applied Mathematics; Director, Center for Excellence and Equality in Education, Rice University
4:35 PM – 4:45 PM	BREAK
4:45 PM – 5:30 PM	DISPARITIES IN HEALTH IN AMERICA – AN OVERVIEW Grand Ballroom J,K
	Lovell A. Jones, PhD, Director and Professor, Center for Health Equity & Evaluation Research, The University of Texas MD Anderson Cancer Center/University of Houston
5:30 PM – 6:00 PM	FACILITATED DISCUSSION
6:30 PM – 7:30 PM	MENTOR ORIENTATION Meeting Room 330
	Marian Johnson-Thompson, PhD, Professor Emerita, Department of Biological Sciences, University of District of Columbia
	Patricia Lee-Robinson, MS, MEd, Associate Provost, Associate Professor of Biology, Chaminade University
	James L. Phillips, MD, Senior Associate Dean and Professor of Pediatrics, Office of Diversity &

Community Outreach, Baylor College of Medicine

Wednesday, June 27



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

WEDNESDAY, JUNE 27, 2012

7:00 AM – 8:00 AM CONTINENTAL BREAKFAST

Grand Ballroom Pre Function J

8:00 AM – 9:45 AM **EDUC**

EDUCATIONAL PROGRAM OVERVIEW & BREAKFAST FOR CREDIT AND NON-CREDIT

STUDENTS

Grand Ballroom J,K

Student Mentoring Track Program Orientation

Marian Johnson-Thompson, PhD, Professor Emeritus, Department of Biological Sciences

University of District of Columbia

Patricia Lee-Robinson, MS, MEd, Associate Provost, Associate Professor of Biology, Chaminade

University

Explanation of Credit & Non-Credit Program Tracks

James L. Phillips, MD, Senior Associate Dean and Professor of Pediatrics, Office of Diversity &

Community Outreach, Baylor College of Medicine

Motivational Speaker for Credit and Non-Credit Program Tracks

Guadalupe Quintanilla, EdD, Associate Professor, Department of Hispanic Studies, University of

Houston

Larry Laufman, EdD, Assistant Professor, Baylor College of Medicine

9:45 AM - 10:00 AM

BREAK

10:00 AM - 12:00 PM

CREDIT AND NON-CREDIT BREAKOUT SESSION & LUNCH

"Health Disparities and the Media Roundtable Discussion"

Grand Ballroom J,K

Moderator:

George A. Strait, Jr., Assistant Commissioner, Food and Drug Administration, Public Affairs, US

Department of Health and Human Services (HHS)

Roundtable Discussants:

Prerna Mona Khanna, MD, MPH, FACP, Medical Contributing Editor, FOX Chicago News

• Kymberle L. Sterling, DrPH, Assistant Professor, Georgia State University. Institute of Public Health, Partnership for Urban Health Research

• Dr. Michael Lenoir, Bay Area Pediatric Group

 William Douglas Evans - (Remotely SKYPED) George Washington University Professor of Prevention and Community Health

• Laurence Payne, Host, Producer of Dialog Houston, HCC TV

12:15 PM – 1:15 PM

CREDIT BREAKOUT SESSION

"Becoming a Media Master"

Grand Ballroom J,K

Prerna Mona Khanna, MD, MPH, FACP, Medical Contributing Editor, FOX Chicago News

1:15 PM - 1:45 PM

FACILITATED DISCUSSION

1:45 PM - 2:00 PM

BREAK

Wednesday-Thursday, June 27-28



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

2:00 PM - 3:00 PM GENES, ETHNICITY AND AUTOIMMUNITY: A HISTORICAL PERSPECTIVE

Grand Ballroom J, K

John D. Reveille, MD, Professor and Director, Division of Rheumatology & Clinical

Immunogenetics, The University of Texas Health Science Center at Houston

3:00 PM – 4:00 PM **HEALTH DISPARITIES & GENETICS**

Grand Ballroom J, K

"Ancestry, Health and Disease: Placing Genetic Susceptibility into Context"

Rick Kittles, PhD, Associate Professor, University of Illinois at Chicago

4:00 PM – 4:30 PM FACILITATED DISCUSSION

4:30 PM - 5:00 PM **BREAK**

5:00 PM - 6:00 PM **OPENING KEYNOTE**

Grand Ballroom A-F

S. Leonard Syme, PhD, Professor of Epidemiology and Community Health. University of

California at Berkeley

6:00 PM – 6:30PM **BREAK**

6:30 PM – 8:30 PM **FOUNDERS' AWARD RECEPTION**

Grand Ballroom H,I,K,L

This award in presented to individual(s) living a personal and professional life that speaks to the reason the Founders created the ICC and who are contributing to its mission. This session will also recognize the First Ladies of the ICC for their tremendous support, outstanding commitment, passion and leadership contributions to the Intercultural Cancer Council over the past 25 years.

Honoree:

Sandral Hullett, MD, MPH, CEO & Medical Director, Cooper Green Hospital

8:30 PM – 10:00 PM **MENTOR/MENTEE EVENT**

Grand Ballroom G,J

THURSDAY, JUNE 28, 2012

6:00 AM – 7:00 AM "EXERCISE YOUR WAY TO GOOD HEALTH"

Awake with the rising sun and jump-start your day by participating in a refreshing exercise

program. Get energized, rejuvenated and ready for another exciting day!

7:00 AM – 7:50 AM **MEET THE EXPERTS BREAKFAST**

Grand Ballroom J,G

7:45 AM – 8:00 AM **SETTING THE STAGE FOR THE DAY**

Grand Ballroom B,C,E,F

Lovell A. Jones, PhD, Director and Professor, Center for Health Equity & Evaluation Research, The

University of Texas MD Anderson Cancer Center/University of Houston



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

8:00 AM - 11:45 AM

"Mapping the Future of Science & Service Towards Health Equity in the Era of Health Reform" $Grand\ Ballroom\ B, C, E, F$

This exciting facilitated panel will feature leaders of key agencies and organizations working to reduce health disparities. Among the issues to be discussed will be challenges and successes in health disparities research, effective translation to communities and community based programs and necessary system changes to make meaningful and measurable reductions in health disparities.

8:00 AM - 8:10 AM

SESSION OVERVIEW

Moderator:

Tom Kean, MPH, President and CEO, C-Change

8:10 AM - 8:50 AM

SETTING THE STAGE

The Evolution of Science and Service in Health Equity

William (Bill) C. Jenkins, MPH, PhD, Disease Transmission Specialist, Former Supervisory Epidemiologist, National Center for HIV, STD, and TB Prevention, Centers for Disease Control and Prevention, US Department of Health and Human Services (HHS)

Current Status of Science and Service in Health Equity

Maureen Lichtveld, MD, MPH, Freeport McMoRan Chair of Environmental Policy, Department of Environmental Health Sciences, Tulane University School of Public Health and Tropical Medicine

Reactor Panel

9:00 AM - 10:00 AM

Panel 1: Mapping the Future of Science towards Health Equity

Topics include:

- Critical research questions going forward
- Research questions necessary to find solutions
- Health services research
- The research workforce
- Innovative research enterprises
- Moving research results into action faster

Panelists:

- Amelie G. Ramirez, DrPH, Director, Institute for Health Promotions Research, The University of Texas Health Science Center, San Antonio
- Kathy Lim Ko, President and CEO, Asian & Pacific Islander American Health Forum
- Roger Bulger, MD, President and CEO (retired), Association of Academic Health Centers
- Allen S. Lichter, MD, CEO, American Society for Clinical Oncology
- **Jeffery Henderson, MD, MPH,** President and CEO, Black Hills Center for American Indian Health, Cheyenne River Sioux Tribe
- Ahmed Calvo, MD, MPH, Senior Medical Officer, Office of Health Information and Technology and Quality, US Department of Health Resources and Services Administration (HHS)
- · Raymond DuBois, MD, PhD, Executive Vice President, UTMD Anderson Cancer Center



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

9:55 AM - 10:15 AM

NETWORKING BREAK & LIGHT SNACK

Pre Function Area

10:15 AM - 11:20 AM

Panel 2: Mapping the Future of Service Towards Health Equity

Topics Include:

- New service delivery models and their potential impact
- The next generation public health agenda
- Major policy drivers
- How to scale up from demonstration projects
- Innovative service programs
- · The service workforce

Panelists:

- Eduardo Sanchez, MD, MPH, Vice-President & CMO, Blue Cross/Blue Shield of Texas
- Wayne S. Rawlins, MD, MBA, National Medical Director, Racial and Ethnic Equality Initiatives, Aetna
- Richard Murray, MD, Vice President, Global Center for Scientific Affairs, Merck & Co., Inc.
- Gary Earl, BA, Vice President for Health Transformation, United Healthcare
- J. Nadine Gracia, MD, MSCE, Deputy Assistant Secretary of Minority Health (Acting), Acting Director of the Office of Minority Health (OMH), US Department of Health and Human Services (HHS)
- Nancy C. Lee, MD, Deputy Assistant Secretary for Health-Women's Health, Director of the Office on Women's Health (OWH), US Department of Health and Human Services (HHS)
- Christina Austin-Valere, PhD, LCSW, Advocacy Director, Board of Directors, American Society of Social Work

11:20 AM - 11:40 AM

SUMMARY: THE FUTURE OF SCIENCE, SERVICE AND HEALTH EQUITY

Kenneth Shine, MD, Executive Vice Chancellor for Health Affairs, University of Texas System Former President, Institute of Medicine

11:40 AM - 11:45 AM

SESSION CLOSING

Tom Kean, MPH, President and CEO, C-Change

11:45 AM – 12:00 PM

BREAK

Grand Ballroom Pre Function Area AD

12:00 PM - 1:45 PM

SUSAN MATSUKO SHINAGAWA LIVESTRONG CANCER CONTROL LEADERSHIP AWARD LUNCHEON

Grand Ballroom H,I,K,L

Presentation of an award to an individual or group whose demonstrated leadership in the area of cancer control goes beyond the expected to the exceptional, through the formulation and execution of policies, programs, partnerships and/or research to eliminate the unequal burden of cancer among racial and ethnic minorities and medically underserved populations.

Speaker:

Robert G. Robinson, MSW, DrPH, Health Power Editor, Smoking and Health, and Race, Culture and Health

1:45 PM – 2:00 PM

BREAK



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

2:00 PM – 8:00 PM BREAKOUT SESSION: HEALTH DISPARITIES & HEALTH COMMUNICATION

Grand Ballroom G, J

2:00 PM – 2:45 PM BREAKOUT SESSION: HEALTH LITERACY MEETS SOCIAL JUSTICE

"WORDS DO COUNT"

Cathy D. Meade, PhD, RN, FAAN, Senior Member, Division of Population Science, Health Outcomes & Behavior, H. Lee Moffitt Cancer Center and Research Institute, Professor, University of South Florida, College of Medicine, Department of Oncologic Sciences

2:00 PM – 2:45 PM BREAKOUT SESSION: THE ROLE OF HEALTH COMMUNICATION IN REDUCING HEALTH

DISPARITIES

Shelly R. Hovick, PhD, Kellogg Health Scholar Postdoctoral Fellow, Center for Health Equity & Evaluation Research, The University of Texas MD Anderson Cancer Center/University of

Houston

3:30 PM – 4:15 PM BREAKOUT SESSION: CULTURAL TAILORING FOR HEALTH PROMOTION PROGRAM

Kenneth Resnicow, PhD, Professor, University of Michigan, School of Public Health

4:15 PM – 4:45 PM FACILITATED DISCUSSION

Grand Ballroom G, J

4:45 PM – 5:00 PM **BREAK**

5:00 PM – 5:45 PM BREAKOUT SESSION: NARROWING THE GAP THROUGH ATTENTION TO VALUES AND

ETHICS IN PUBLIC HEALTH RISKASSESSMENT

Grand Ballroom G,J

Colin L. Soskolne, PhD, FACE, Department of Public Health Sciences, School of Public

Health, University of Alberta

5:45 PM - 6:30 PM BREAKOUT SESSION: ADDRESSING THE SOCIO-ECONOMIC DETERMINANTS OF

HEALTH AS A MATTER OF SOCIAL JUSTICE

William (Bill) C. Jenkins, MPH, PhD, Disease Transmission Specialist, Former Supervisory

 $Epidemiologist\ at\ the\ CDC's\ National\ Center\ for\ HIV,\ STD,\ and\ TB\ Prevention,\ US$

Department of Health and Human Services (HHS)

6:30 PM – 7:15 PM BREAKOUT SESSION: THE ESSENTIALS: ETHICS, PROFESSIONALISM AND LEADERSHIP

Janice Allen Chilton, DrPH, MA, MPH, MCHES, CPH, Director, MD Anderson

Bioethics Initiative for Equity in Health Care and Research, Center for Health Equity & Evaluation Research, The University of Texas MD Anderson Cancer Center/University of

Houston

7:15 PM – 8:00 PM FACILITATED DISCUSSION

Friday, June 29



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

FRIDAY, JUNE 29, 2012

6:00 AM – 7:00 AM "EXERCISE YOUR WAY TO GOOD HEALTH"

Awake with the rising sun and jump-start your day by participating in a refreshing exercise program. Get energized, rejuvenated and ready for another exciting day!

7:00 AM - 8:00 AM CONTINENTAL BREAKFAST

Grand Ballroom Pre Function Area AD

8:00 AM - 8:15 AM **SETTING THE STAGE FOR THE DAY**

Grand Ballroom B,C,E,F

COL (Ret.) James E. Williams, Jr., MD, SPHR, ICC Immediate Past Chair

8:15 AM - 11:45 AM CHARTING NEW INITIATIVES IN HEALTH DISPARITIES – OVERVIEW

A panel of community individuals and/or organizations from previous HOPE (Helping Other People Endure) Award winners will share best practices in mobilizing communities to address health disparities, whether through programs and/or policy development and implementation. In follow-up to this panel, leaders from key federal agencies will present new initiatives (intra- and interagency) to address health disparities. They will also provide comment on HOPE/Community initiatives and how the community perspective might influence future RFA development, provision of technical assistance and capacity building and other programmatic areas. Time will be allotted for facilitated discussion with the larger audience.

Chair:

Nancy C. Lee, MD, Deputy Assistant Secretary for Health-Women's Health, Director of the Office on Women's Health (OWH), US Department of Health and Human Services (HHS)

Panel 1: HOPE Awardees

Lawrence W. McRae, President/CEO, McRae Prostate Cancer Awareness Foundation

Venus Ginés, MA P/CHWI, CEO/Founder, Día de la Mujer Latina™ Inc

Celeste (CeCe) Whitewolf, JD, Native People's Circle of Hope

Victor Kaiwi Pang, Pacific Islander Health Partnerships

Ann Duesing, Board Member, Mountain Empire Older Citizens, Inc / Mountain Laurel Cancer Resource and Support Center

Panel 2: Federal agency representatives

Ahmed Calvo, MD, MPH, Senior Medical Officer, Office of Health Information and Technology and Quality, Health Resources and Services Administration, HHS

Lumbé Davis, DHSc, MPH, CHES, Communication and Training Team, Comprehensive Cancer Control Program, Centers for Disease Control and Prevention, US Department of Health and Human Services (HHS)

Nancy C. Lee, MD, Deputy Assistant Secretary for Health-Women's Health, Director of the Office on Women's Health (OWH), US Department of Health and Human Services (HHS)

Short break

Discussants:

Harold P. Freeman, MD, President and Founder, Ralph Lauren Center for Cancer Care and Prevention, Senior Advisor to Director of the National Cancer Institute **Tasha Tilghman-Bryant, MPA**, Manager, Strategic Initiatives, C-Change

Facilitated questions and answers from the audience

Friday-Saturday, June 29-30



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY **UNDERSERVED & HEALTH EQUITY**

Empowering Communities in the Era of Health Care Reform

11:45 AM - 12:00PM **BREAK**

12:00 PM - 1:45 PM HERBERT W. NICKENS MEMORIAL LECTURESHIP LUNCHEON

Grand Ballroom H,I,K,L

Speaker & Honoree:

David Satcher, MD, PhD, Director, The Satcher Health Leadership Institute and, Center of Excellence on Health Disparities, Poussaint-Satcher-Cosby Chair in Mental Health, Morehouse

School of Medicine, 16th Surgeon General of the United States

BREAK 1:45 PM - 2:00 PM

2:00 PM - 5:00 PM PROFESSIONAL AND STUDENT ORAL PRESENTATIONS

Third Floor Meeting Room

6:00 PM - 9:00 PM HEIGHT & HOPE AWARDS CELEBRATION

Grand Ballroom G-L

LET'S CELEBRATE! The Height and HOPE (Helping Other People Endure) Awards will be announced and presented during a rousing reception and celebration featuring multi-cultural foods and entertainment. Please feel free to dress in attire representative of your cultural background.

Dorothy I. Height Honoree:

Marilyn Hughes Gaston, MD, Former Assistant Surgeon General and Director, Bureau of Primary Health Care, US Public Health Service Rear Admiral, USPHS, Ret., Co-Director, The Gaston and Porter Health Improvement Center

SATURDAY, JUNE 30, 2012

"EXERCISE YOUR WAY TO GOOD HEALTH" 6:00 AM - 7:00 AM

Awake with the rising sun and jump-start your day by participating in a refreshing exercise

program. Get energized, rejuvenated and ready for another exciting day!

REGISTRATION 7:00 AM - 5:00 PM

7:00 AM - 8:30 AM BREAKFAST SESSION - HAROLD P. FREEMAN LECTURESHIP

Grand Ballroom H.I.K.L

Harold P. Freeman, MD, President and Founder, Ralph Lauren Center for Cancer Care and Prevention, Senior Advisor to Director of the National Cancer Institute

Speaker & Honoree

Billy U. Philips, Jr., PhD, MHA, Vice President for Rural and Community Health, Texas Tech

University Health Sciences Center

8:30 AM - 8:45 AM SETTING THE STAGE FOR THE DAY

> Lee Buenconsejo-Lum MD, FAAFP, Program Chair, 25th Anniversary of the Biennial Symposium on Minorities, the Medically Underserved and Health Equity; Associate Professor, Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of Hawaii



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

8:45 AM - 10:15 AM

CHRONIC DISEASE PREVENTION AND CONTROL

Grand Ballroom H,I,K,L

Social Justice Concerns in Stemming the Tobacco, Diabetes and Obesity Epidemics in the Era of Obama Care

Chair:

Amber E. Bullock, MPH, CHES, Executive Vice President, Program Development LEGACY

Sponsored by Legacy, this panel will highlight the life-saving role of preventing and controlling risk factors for chronic disease and cancer: tobacco prevention and control, community-based strategies for addressing poor diet, lack of physical activity and addressing the social determinants of health. The panelists will discuss efforts and needed strategies to ensure that chronic disease prevention becomes a sustainable reality for communities of color with health care reform, while keeping social justice issues front and center for prevention work.

- "Health and Place Matters Social Determinants for Prevention"
 Marjorie A. Paloma, MPH, Senior Policy Advisor, RWJF Health Group
- "Hope and Audacity: Social Justice Prevention Perspective"
 Makani Themba-Nixon, Executive Director, Praxis Project
- "Mobilizing Local, National and International Resources to Address Needs in Resource Limited Settings: A Reality Check"
 - **Neal A. Palafox, MD, MPH,** Principal Investigator, Pacific Center of Excellence in the Elimination of Disparities, Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of Hawaii
- "Strategies to Sustain the Tobacco Control Movement: Impact on Communities of Color"
 Kevin Collins, PhD, Deputy Branch Chief (Acting), Epidemiology Branch, Office of Smoking and Health, Centers for Disease Control and Prevention (CDC), US Department of Health and Human Services (HHS)

Discussant:

Dileep G. Bal, MD, MS, MPH, ICC Chair

FACILITATED DISCUSSION

Short Break

10:30 AM -12:00 PM

Continuation of Chronic Disease Prevention and Control Panel

- "Tobacco Related Disparities: Menthol Wars"
 Phillip Gardiner, DrPH, Social & Behavioral Sciences and Neurosciences and Nicotine
 Dependence Research Administrator for the Tobacco Related Disease Research Program
 (TRDRP), University of California Office of the President
- "The Obesity Epidemic Utilizing Lessons from the Tobacco Control Movement & Pearls of Wisdom From the Obesity Forefronts"
 - **Rod Lew, MPH**, Executive Director, Asian Pacific Partners for Empowerment Advocacy and Leadership (APPEAL)
- "Diabetes Prevention and Management Among Pacific Islanders"
 Nia Aitaoto, MPH, MS, PhD(c), Principal Investigator, Faith in Action Research Alliance
- "Controlling Chronic Disease in Indigenous Populations"
 Linda Burhansstipanov, MSPH, DrPH, (Cherokee Nation of Oklahoma), Founder/President
 Native American Cancer Research

FACILITATED DISCUSSION



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

12:15 PM - 2:00 PM

THE GREAT AMERICAN POSTER PICNIC

Grand Ballroom A,B,D,E

Professional, community and student poster presentations depicting research projects set in a relaxed, traditional all-American picnic environment.

2:00 PM - 3:15 PM

THE FUTURE OF THE AFFORDABLE CARE ACT AT THE FEDERAL AND STATE LEVELS

Meeting Room 335 A

This session will provide participants an in-depth insight of where we are now and a glimpse of where we will be in the future with regard to the proposed health care act. Participants will receive the most current information about the affordable healthcare act and how it will affect them individually. Topics will include the underinsured, disparity issues and access to care.

Presenters:

Jennie R. Cook, President, ICC Caucus, Past Chairman, National Board of Directors, American Cancer Society

Citseko Staples Miller, Senior Specialist, State and Local Campaigns, American Cancer Society Cancer Action Network, Inc.

3:30 PM - 4:45 PM

SOCIAL JUSTICE: RE-LIGHTING THE FIRE

Meeting Room 335 A

Panelists in this special session will challenge participants to discuss ways to mobilize minority and medically underserved communities to be effective advocates for change.

Dileep G. Bal, MD, MS, MPH, ICC Chair

Recorder: Mavis Nitta, MPH, CHES, Legacy Project Coordinator, Pacific Center of Excellence in the Elimination of Disparities, Department of Family Medicine and Community Health, University of Hawaii

2:00 PM - 4:45 PM

COMMUNITY-BASED SUCCESS STORIES Breakout sessions

Participants will have the opportunity to attend breakout sessions organized around thematic areas critical to community-based efforts to reduce health disparities. Each session will include up to 3 panelists and time for a facilitated discussion about next steps and recommendations to further the system improvements required to effect meaningful change. These recommendations will be reported to the large group on Sunday morning and will be used to guide strategic priorities for the ICC and other organizations.

Breakout sessions/focus areas:

2:00 PM - 3:15 PM

BREAKOUT SESSION: ENGAGING POLICY MAKERS

Meeting Room 340B

This session will highlight community-driven efforts to engage policy makers which have resulted in policy changes that have or will impact chronic disease prevention, control and/or treatment.

Moderator: Neal A. Palafox, MD, MPH, Principal Investigator, Pacific Center of Excellence in the Elimination of Disparities, John A. Burns School of Medicine, University of Hawaii Recorder: LaKeisha Batts, PhD, Kellogg Health Scholar Postdoctoral Fellow, Center for Health Equity & Evaluation Research, The University of Texas MD Anderson Cancer Center/University of Houston



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

2:00 PM - 3:15 PM

BREAKOUT SESSION: BUILDING/MAINTAINING COALITIONS

Meeting Room 339 A

This session will highlight successful strategies or innovative approaches used to build, re-build or maintain active coalitions focused on control of cancer or chronic disease.

Moderator: Frankie Denise Powell, PhD, Associate Professor, School of Education B-K Program, University of North Carolina at Pembroke

Recorder: Patricia A. Torris, MPA, Program Manager, Pacific Regional Central Cancer Registry, Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of Hawaii

2:00 PM - 3:15 PM

BREAKOUT SESSION: SCREENING-FOCUSED SUCCESSES

Meeting Room 339 B

This session will highlight community-based efforts to improve screening for chronic disease in populations with reduced rates of screening services.

Moderator: Bonnie Wheatley, MPH, MA, EdD, Vice-President, Zephyrus Group, LLC *Recorder:* Celeste Whitewolf (CeCe), JD, Native People's Circle of Hope

2:00 PM - 3:15 PM

BREAKOUT SESSION: SURVIVORSHIP-FOCUSED SUCCESSES

Meeting Room 340 A

This session will highlight community-based efforts to improve the quality of life for persons diagnosed with cancer or late-stage chronic disease.

Moderator: Patricia K. Bradley, PhD, RN, Associate Professor, College of Nursing, Villanova University

Recorder: Stacy Lloyd, PhD, Kellogg Health Scholar Postdoctoral Fellow, Center for Health Equity & Evaluation Research, The University of Texas MD Anderson Cancer Center/University of Houston

3:30 PM – 4:45 PM

BREAKOUT SESSION: BUILDING/MAINTAINING COALITIONS - B

Meeting Room 335 A

This session will highlight successful strategies or innovative approaches used to build, re-build or maintain active coalitions focused on control of cancer or chronic disease.

Moderator: Neal Palafox, MD, MPH, Principal Investigator, Pacific Center of Excellence in the Elimination of Disparities, John A. Burns School of Medicine, University of Hawaii *Recorder:* Denae W. King, PhD, Assistant Professor, The University of Texas Health Science Center at Tyler

3:30 PM - 4:45 PM

BREAKOUT SESSION: SOCIAL DETERMINANTS (HOUSING, POVERTY, EDUCATION)

Meeting Room 340 A

This session will highlight projects with demonstrated improvement in health outcomes, based on work primarily addressing reduction of poverty, improvements in education and/or the living environment.



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

Moderator: Carlos Gallego MEd, Outreach Manager, Think Small, Minneapolis *Recorder:* Frankie Denise Powell, PhD, Associate Professor, School of Education, B-K Program, University of North Carolina at Pembroke

3:30 PM - 4:45 PM

BREAKOUT SESSION: PREVENTION-FOCUSED SUCCESSES

Meeting Room 339 A

This session will highlight projects resulting in improvements in risk factors for developing chronic diseases, including cancer.

Moderator: Celeste Whitewolf (CeCe), JD, Native People's Circle of Hope *Recorder:* Bonnie Wheatley, MPH, MA, EdD, Vice-President, Zephyrus Group, LLC

3:30 PM - 4:45 PM

BREAKOUT SESSION: TREATMENT / ACCESS TO TREATMENT

Meeting Room 339 B

This session will highlight projects resulting in improved treatment or access to treatment for cancer or other chronic diseases.

Moderator: Sharon Barrett, MS, DrPH(c), Founder and Principal for S.E.B. and Associates *Recorder:* Kimberly Enard, PhD, RN, Postdoctoral Fellow, The University of Texas MD Anderson Cancer Center

3:30 PM - 4:45 PM

SURVIVORSHIP MEETING

Meeting Room 340B

As cancer diagnosis and treatment have advanced, often cancer patients live for many years and have a myriad of physical and emotional issues to manage. In addition, the broad diversity of cancer survivors requires us to consider multi-cultural aspects of survivorship. This breakout session will include perspectives of researchers and community advocates regarding the issues facing diverse cancer survivors and the opportunities to address these issues.

Chair:

Linda Fleisher, MPH, PhD(c), Assistant Vice President, Health Communications and Health Disparities, Fox Chase Cancer Center

Panelists:

Diana D. Jeffery, PhD, Director, Center for Healthcare Management Studies Health Program Analysis and Evaluation TRICARE, Management Activity Military Health System Assistant Secretary of Defense, Health Affairs

Westley Sholes, MPA, Vice President of Health Programs, National Association of Black County Officials

Patricia K. Bradley, PhD, RN, Associate Professor, College of Nursing, Villanova University **Kimlin Tam Ashing-Giwa, PhD,** Professor and Founding Director, Center of Community Alliance for Research and Education, Division of Population Sciences, City of Hope

Maria Guerra- Sanchez, RN, CCRP, Tender Drops of Love

Furjen Deng, PhD, Light and Salt

6:00 PM - 6:45 PM

RECEPTION

Grand Ballroom G,J

Saturday, June 30 - Sunday, July 1



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

7:00 PM - 9:00 PM

LASALLE D. LEFFALL, JR. AWARDS BANQUET & GALA

Grand Ballroom H,I,K,L

Recognizes individuals and organizations that have distinguished themselves in addressing the cancer crisis in minority and medically underserved communities through educational programs, clinical service, research, or public awareness.

HONOREE

Neal A. Palafox, MD, MPH, Principal Investigator, Pacific Center of Excellence in the Elimination of Disparities, Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of Hawaii

LEAP OF FAITH AWARD

The Leap of Faith award recognizes an organization and/or individual who has come forward at critical moments to support the mission, ideas and efforts of the Biennial Symposium Series and/or the Intercultural Cancer Council.

Honoree:

University of Houston, accepting on behalf of the university **John Antel, PhD,** Provost and Senior Vice President

SUNDAY, JULY 1, 2012

6:00 AM - 7:00 AM

"EXERCISE YOUR WAY TO GOOD HEALTH"

Awake with the rising sun and jump-start your day by participating in a refreshing exercise program. Get energized, rejuvenated and ready for another exciting day!

7:30 AM - 9:00 AM

CONTINENTAL BREAKFAST

7:00 AM - 8:00 AM

MEET THE EXPERTS BREAKFAST SERIES

Grand Ballroom A,D

8:00 AM - 10:30 AM

CREDIT BREAKOUT SESSION CONCENTRATION – HEALTH DISPARITIES & HEALTH POLICY

Grand Ballroom A,D

Moderator: John Estrada, MD, Associate Professor of Pediatrics, Department of Pediatrics, Children's Hospital, Louisiana State University Health Sciences Center, School of Medicine at New Orleans

 $8:00\,AM - 8:45AM$

BREAKOUT SESSION: ENVIRONMENTAL FACTORS AND SOCIAL DETERMINANTS: HOW HEALTH POLICY NEEDS TO ADAPT

John Estrada, MD, Associate Professor of Pediatrics, Department of Pediatrics, Children's Hospital, Louisiana State University Health Sciences Center, School of Medicine at New Orleans



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

8:45AM - 9:30 AM

BREAKOUT SESSION: WOMEN, MEN AND HEALTH EQUITY: A MODEL FOR HEALTH

POLICY

Justina Trott, MD, FACP, Senior Fellow and Co-Director, Women's Health Policy Unit, RWJF Center for Health Policy University of New Mexico, Clinical Professor of Medicine University of New Mexico, Advisor to Women's Health Services, National Community Center of Excellence in Women's Health, Robert Wood Johnson Health Policy Fellow

9:30 AM – 10:15AM BREAKOUT SESSION: AMERICAN INDIAN HEALTH DISPARITIES & HEALTH POLICIES:

POLICY MATTERS!

Judith S. Kaur, MA, MD, Professor of Oncology, Mayo Clinic College of Medicine, Medical

Director for Native American Programs, Mayo Comprehensive Cancer Center

10:15 AM – 10:30 AM

FACILITATED DISCUSSION

10:00 AM - 11:15 AM

PLENARY SESSION Grand Ballroom H,I,K,L

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10:00 AM - 10:45 AM

VOICES FROM THE COMMUNITY:

Report out from the community breakout sessions on priority areas

Lee Buenconsejo-Lum MD, FAAFP, Program Chair, 25th Anniversary of the Biennial Symposium on Minorities, the Medically Underserved and Health Equity, Associate Professor, Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of

Hawaii

10:45 AM - 11:15 AM

REFLECTIONS AND NEXT STEPS:

Honorary Chairs:

Charles A. LeMaistre, MD, Former President, The University of Texas MD Anderson Cancer Center

and Former Chancellor, The University of Texas

Pamela M. Jackson, MS, Interim Executive Director, Intercultural Cancer Council

Betty Lee Hawks, MA, Former Special Assistant to the Director, Office of Minority Health,

Department of Health and Human Services; APPEAL Board Chair

Harold P. Freeman, MD, President and Founder, Ralph Lauren Center for Cancer Care and

Prevention, Senior Advisor to Director of the National Cancer Institute

Dileep G. Bal, MD, MS, MPH, ICC Chair

11:15 AM – 11:30 AM

BREAK

11:30 AM – 1:00 PM

FAREWELL JAZZ BRUNCH - MAJOR KEYNOTE SPEAKER

Grand Ballroom H,I,K,L

1:00 PM

EVALUATION AND ADJOURNMENT

Tuesday/Wednesday, June 26 & 27



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

Students Non-Credit Only Program

TUESDAY, JUNE 26, 2012

6:30 PM - 7:30 PM

MENTOR ORIENTATION

Meeting Room 330

Marian Johnson-Thompson, PhD, Professor Emerita, Department of Biological Sciences,

University of District of Columbia

Patricia Lee-Robinson, MS, MEd, Associate Provost, Associate Professor of Biology,

Chaminade University

James L. Phillips, MD, Senior Associate Dean and Professor of Pediatrics, Office of Diversity &

Community Outreach, Baylor College of Medicine

WEDNESDAY, JUNE 27, 2012

7:00 AM - 8:00 AM

Continental Breakfast

Grand Ballroom Pre Function K,L

8:00 AM - 9:45 AM

EDUCATIONAL PROGRAM OVERVIEW & BREAKFAST FOR ACADEMIC AND NON

ACADEMIC STUDENTS

Grand Ballroom J,K

Student Mentoring Track Program Orientation

Marian Johnson-Thompson, PhD, Professor Emerita, Department of Biological

Sciences, University of District of Columbia

Patricia Lee-Robinson, MS, MEd, Associate Provost, Associate Professor of Biology,

Chaminade University

Explanation of Academic & Non Academic Program Tracks

James L. Phillips, MD, Senior Associate Dean and Professor of Pediatrics, Office of

Diversity & Community Outreach, Baylor College of Medicine

Larry Laufman, EdD, Assistant Professor, Baylor College of Medicine

Motivational Speaker for Academic and Non Academic Program Tracks

Guadalupe Quintanilla, EdD, Associate Professor, Department of Hispanic Studies

University of Houston

9:45 AM - 10:00 AM

BREAK

10:00 AM – 12:00 PM

CREDIT and NON-CREDIT BREAKOUT SESSION and LUNCH

"Health Disparities and the Media Roundtable Discussion"

Grand Ballroom J,K

Moderator:

George A. Strait, Jr., Assistant Commissioner, Food and Drug Administration, Public Affairs,

US Department of Health and Human Services (HHS)

Wednesday, June 27



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

Roundtable Discussants:

- · Prerna Mona Khanna, MD, MPH, FACP, Medical Contributing Editor, FOX Chicago News
- **Kymberle L. Sterling, DrPH,** Assistant Professor, Georgia State University Institute of Public Health, Partnership for Urban Health Research
- Michael Lenoir, MD, Bay Area Pediatric Group
- William Douglas Evans, PhD, (Remotely SKYPED) George Washington University Professor of Prevention and Community Health
- Laurence Payne, Host, Producer of Dialog Houston, HCC TV

12:15 PM - 1:00 PM

PANEL 1 PURSUING A BIOMEDICAL CAREER

Grand Ballroom H

Moderator: Charleta Guillory, MD, Associate Professor of Pediatrics-Neonatology, Baylor College of Medicine, Associate Medical Director, Level 2 Nursery, Director, Neonatal-Perinatal Public Health Program - Texas Children's Hospital

- "Opportunities To Enhance Your Career Plans"
- "Preparing for/Tools for Success in Graduate School"
 Frank Talamantes, PhD, Professor Emeritus, University of California Santa Cruz
- "Preparing for/Tools for Success in Professional School"
 James L. Phillips, MD, Senior Associate Dean and Professor of Pediatrics, Office of Diversity and Community Outreach, Baylor College of Medicine
- "How to Choose a Mentor"
 Marian Johnson-Thompson, PhD, Professor Emerita, Department of Biological Sciences, University of District of Columbia

1:00 PM - 1:15 PM

FACILITATED DISCUSSION

Grand Ballroom I

1:30 PM - 5:00 PM

OPENING CEREMONY

Grand Ballroom A-F

Taiko Drummers

Chanter

COLOR GUARD

NATIONAL ANTHEM

INVOCATION

Jose Cedillo, Manager, Chaplaincy and Pastoral Education, The University of Texas MD Anderson Cancer Center

OPENING REMARKS

SETTING THE STAGE

Dileep G. Bal, MD, MS, MPH, Intercultural Cancer Council Chair

Honorary Chairs:

Charles A. LeMaistre, MD, Former President, The University of Texas MD Anderson Cancer Center and Former Chancellor, The University of Texas

Pamela M. Jackson, MS, Interim Executive Director, Intercultural Cancer Council *Betty Lee Hawks, MA,* Former Special Assistant to the Director, Office of Minority Health, Department of Health and Human Services; APPEAL Board Chair

Harold P. Freeman, MD, President and Founder, Ralph Lauren Center for Cancer Care and Prevention, Senior Advisor to Director of the National Cancer Institute

Wednesday, June 27



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

WELCOME FROM PUBLIC OFFICIALS

The Honorable Sheila Jackson Lee, 18th Congressional District Mayor Pro Tem Ed Gonzalez, City of Houston

SURVIVOR'S PROMENADE

Grand Marshall: Venus Ginés, MA, P/CHWI, CEO/Founder, Día de la Mujer Latina™ Inc

MUSICAL SELECTION

REFLECTION PERIOD

COL (Ret.) James E. Williams, Jr., MS, SPHR, ICC Immediate Past Chair

Honoring the ICC Board Members who have passed away

REMARKS ON BEHALF OF THE SURVIVORS

"Quo vadis ICC: Past, Present Future"

Marjorie Kagawa-Singer, PhD, MA, MN, RN, FAAN, Faculty Associate, UCLA Center for Health Policy Research, Professor, UCLA School of Public Health and Department of Asian American Studies

5:00 PM - 6:00 PM

OPENING KEYNOTE

Grand Ballroom A-F

S. Leonard Syme, PhD, Professor of Epidemiology and Community Health, University of California at Berkeley

6:00 PM - 6:30 PM

BREAK

6:30 PM - 8:30 PM

FOUNDERS' AWARD RECEPTION

Grand Ballroom H, J, K, L

This award in presented to individual(s) living a personal and professional life that speaks to the reason the Founders created the ICC and who are contributing to its mission. This session will also recognize the First Ladies of the ICC for their tremendous support, outstanding commitment, passion and leadership contributions to the Intercultural Cancer Council over the past 25 years.

Honoree:

Sandral Hullett, MD, MPH, CEO & Medical Director, Cooper Green Hospital

8:30 PM - 10:00 PM

MENTOR/MENTEE EVENT

Grand Ballroom G, J



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

THURSDAY, JUNE 28, 2012

6:00 AM – 7:00 AM "EXERCISE YOUR WAY TO GOOD HEALTH"

Awake with the rising sun and jump-start your day by participating in a refreshing exercise

program. Get energized, rejuvenated and ready for another exciting day!

7:00 AM – 8:00 AM **CONTINENTAL BREAKFAST**

Grand Ballroom Pre Function Area G

7:00 AM – 5:00 PM **REGISTRATION**

7:45 AM – 8:00 AM **SETTING THE STAGE FOR THE DAY**

Grand Ballroom B,C,E,F

Lovell A. Jones, PhD, Director and Professor, Center for Health Equity & Evaluation Research, The

University of Texas MD Anderson Cancer Center/University of Houston

8:00 AM - 11:45 AM "Mapping the Future of Science and Service Towards Health Equity in the Era of Health

Reform"

Grand Ballroom B,C,E,F

This exciting facilitated panel will feature leaders of key agencies and organizations working to reduce health disparities. Among the issues to be discussed will be challenges and successes in health disparities research, effective translation to communities and community based programs and necessary system changes to make meaningful and measurable reductions in health

disparities.

8:00 AM – 8:10 AM SESSION OVERVIEW

Moderator:

Tom Kean, MPH, President and CEO, C-Change

8:10 AM – 8:50 AM **SETTING THE STAGE**

The Evolution of Science and Service in Health Equity

William (Bill) C. Jenkins, MPH, PhD, Disease Transmission Specialist, Former Supervisory Epidemiologist, National Center for HIV, STD, and TB Prevention, Centers for Disease Control and Prevention, US Department of Health and Human Services (HHS)

Current Status of Science and Service in Health Equity

Maureen Lichtveld, MD, MPH

Freeport McMoRan Chair of Environmental Policy Department of Environmental Health Sciences

Tulane University School of Public Health and Tropical Medicine

REACTOR PANEL

9:00 AM – 10:00 AM Panel 1: Mapping the Future of Science towards Health Equity

Topics include:

- · Critical research questions going forward
- · Research questions necessary to find solutions
- · Health services research
- The research workforce



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

- Innovative research enterprises
- · Moving research results into action faster

Panelists:

- Amelie G. Ramirez, DrPH, Director, Institute for Health Promotions Research, University of Texas Health Science Center, San Antonio
- Kathy Ko, President and CEO, Asian & Pacific Islander American Health Forum
- Robert Burger, MD, President and CEO (retired), Association of Academic Health Centers
- Allen S. Lichter, MD, CEO, American Society for Clinical Oncology
- **Jeffery Henderson, MD, MPH,** President and CEO, Black Hills Center for American Indian Health, Cheyenne River Sioux Tribe
- Ahmed Calvo, MD, MPH, Senior Medical Officer, Office of Health Information and Technology and Quality, US Department of Health Resources and Services Administration (HHS)
- Raymond DuBois, MD, PhD, Executive Vice President, The University of Texas MD Anderson Cancer Center

9:55 AM - 10:15 AM

NETWORKING BREAK & LIGHT SNACK

Pre Function Area

10:15 AM - 11:20 AM

Panel 2: Mapping the Future of Service towards Health Equity

Topics include:

- New service delivery models and their potential impact
- The next generation public health agenda
- Major policy drivers
- How to scale up from demonstration projects
- Innovative service programs
- The service workforce

Panelists:

- Eduardo Sanchez, MD, MPH, Vice-President & CMO, Blue Cross/Blue Shield of Texas
- Wayne S. Rawlins, MD, MBA, National Medical Director, Racial and Ethnic Equality Initiatives, Aetna
- Richard Murray, MD, Vice President, Global Center for Scientific Affairs, Merck & Co., Inc.
- Gary Earl, BA, Vice President for Health Transformation, United Healthcare
- J. Nadine Gracia, MD, MSCE, Deputy Assistant Secretary of Minority Health (Acting), Acting Director of the Office of Minority Health (OMH), US Department of Health and Human Services (HHS)
- Nancy C. Lee, MD, Deputy Assistant Secretary for Health-Women's Health, Director of the Office on Women's Health (OWH), US Department of Health and Human Services (HHS)
- Christina Austin-Valere, PhD, LCSW, Advocacy Director, Board of Directors, American Society
 of Social Work

11:20 AM – 11:40 AM

Summary: The Future of Science, Service and Health Equity

Kenneth Shine, MD, Executive Vice Chancellor for Health Affairs, University of Texas System, Former President. Institute of Medicine

11:40 AM – 11:45 AM

SESSION CLOSING Tom Kean, MPH

11:45 AM - 12:00 PM

BREAK



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

12:00 PM - 1:45 PM

SUSAN MATSUKO SHINAGAWA LIVESTRONG CANCER CONTROL LEADERSHIP AWARD LUNCHEON

Grand Ballroom H,I,K,L

Presentation of an award to an individual or group whose demonstrated leadership in the area of cancer control goes beyond the expected to the exceptional, through the formulation and execution of policies, programs, partnerships and/or research to eliminate the unequal burden of cancer among racial and ethnic minorities and medically underserved populations.

Speaker:

Robert G. Robinson, MSW, DrPH, Health Power Editor, Smoking and Health, and Race, Culture and Health

Honorees:

COL (Ret.) James E. Williams, Jr., MS, SPHR, ICC Immediate Past Chair

Olga G. Sanchez, Community Health Program Representative, Moores Cancer Center, University of California, San Diego

1:45 PM - 2:00 PM

BREAK

2:00 PM - 3:30 PM

RESEARCH AND OUTREACH PANEL (NON-CREDIT)

Meeting Room 339 A,B

Moderator: La Tanya Love, MD, Assistant Professor of Pediatrics and Internal Medicine, Assistant Dean for Admissions and Student Health, Medical Director, Student Health Services, University of Texas Health Science Center at Houston Medical School

• "Biomedical Research and Academia"

Jesus G. Vallejo, MD, Associate Professor, Pediatrics-Infectious Disease, Baylor College of Medicine

"Biomedical Research and Industry"

Richard Murray, M.D., Medical Director, Merck Pharmaceutical

• "Clinical Research"

Thelma Hurd, MD, Associate Professor, Director, Breast Surgery Program, Division of Surgical Oncology, University of Texas Health Science Center at San Antonio

• "Public Health Outreach and Education"

Ngina Lythcott, RN, MSW, DrPH, Associate Dean of Students, Boston University School of Public Health

3:30 PM – 3:45 PM

FACILITATED DISCUSSION

Meeting Room 339 A&B

4:00 PM - 5:30 PM

ROUND TABLE OF PROFESSIONS

Meeting Room 339 A&B

This event is an opportunity for you to meet different successful professionals who work in a variety of different disciplines within the health and science arena. This speed-dating style session will give you a window into the career of each professional and an opportunity to ask questions in a small group setting.

Thursday-Friday, June 28-29



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

Ana M. Navarro, PhD, Associate Professor of Family and Preventive Medicine, University of California, San Diego, UC San Diego Cancer Center

Jeffrey Guidry, PhD, Associate Professor, Department of Health and Kinesiology, Texas A&M University

Ngina Lythcott, RN, MSW, DrPH, Associate Dean of Students, Boston University School of Public Health

Neal A. Palafox, MD, MPH, Professor and former Chair, Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of Hawaii

Frank Talamantes, PhD, Professor Emeritus, University of California

Santa Cruz

Barbara Terry-Koroma, PhD, Program Manager, Department of Defense/US Army, Minority and Underserved Populations Program Manager

Lauree Thomas, MD, Associate Dean for Student Affairs and Admissions, University of Texas Medical Branch School of Medicine

LaTanya J. Love, MD, Assistant Professor of Pediatrics and Internal Medicine, Assistant Dean for Admissions and Student Health, Medical Director, Student Health Services, University of Texas Health Science Center at Houston Medical School

Doris Browne, MD, MPH, Browne and Associates, Inc., Washington, DC **Carlos Gallego MEd,** Outreach Manager, Think Small, Minneapolis

Frankie Denise Powell, PhD, Associate Professor, School of Education, B-K Program, University of North Carolina at Pembroke

Bonnie Wheatley, MPH, MA, EdD, Vice-President, Zephyrus Group, LLC, Piedmont, CA

5:30 PM - 6:30 PM

Continuation of MARKETPLACE OF IDEAS: "MAKING CONNECTIONS TO REDUCE HEALTH INEQUITIES"

Grand Ballroom B,C,E,F

The Marketplace of Ideas symbolizes our effort to create an exciting and informative conference that will stimulate the exchange of ideas, information and resources. The Marketplace will enable all to gather valuable tools for the communities we serve, including the promotion of cancer awareness, screening, treatment, quality of life and health equity in the minority and the medically underserved. Sponsored by ICC Regional Network Leaders, the Marketplace of Ideas is a special networking event designed to help attendees learn about resources available from Resource Providers from local, state, national, federal, non-profit, and for-profit agencies and organizations. Through this event, Community-Based Organizations (CBOs) can connect with national, state and local partners to chart a new course together. Partners and CBOs can identify specific ways to work together to eliminate health disparities and health inequities at the local level.

FRIDAY, JUNE 29, 2012

6:00 AM – 7:00 AM "EXERCISE YOUR WAY TO GOOD HEALTH"

Awake with the rising sun and jump-start your day by participating in a refreshing exercise

program. Get energized, rejuvenated and ready for another exciting day!

7:00 AM – 5:00 PM **REGISTRATION**

7:00 AM - 8:00 AM **CONTINENTAL BREAKFAST**

Grand Ballroom Pre Function Area J

8:00 AM - 8:15 AM **SETTING THE STAGE FOR THE DAY**

Grand Ballroom B,C,E,F

COL (Ret.) James E. Williams, Jr., MD, SPHR, ICC Immediate Past Chair

Friday, June 29



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

8:15 AM - 11:45 AM

CHARTING NEW INITIATIVES IN HEALTH DISPARITIES - OVERVIEW

Grand Ballroom B,C,E,F

A panel of community individuals and/or organizations from previous HOPE Award (Helping Other People Endure) winners will share best practices in mobilizing communities to address health disparities, whether through programs and/or policy development and implementation. In follow-up to this panel, leaders from key federal agencies will present new initiatives (intra- and interagency) to address health disparities. They will also provide comment on HOPE/Community initiatives and how the community perspective might influence future RFA development, provision of technical assistance and capacity building and other programmatic areas. Time will allotted for facilitated discussion with the larger audience.

Chair

Nancy C. Lee, MD, Deputy Assistant Secretary for Health-Women's Health, Director of the Office on Women's Health (OWH), US Department of Health and Human Services (HHS)

Panel 1: HOPE Awardees

Lawrence W. McRae, President/CEO, McRae Prostate Cancer Awareness Foundation Venus Ginés, MA, P/CHWI CEO/Founder, Día de la Mujer Latina™ Inc CeCe Whitewolf, JD, Native People's Circle of Hope Victor Kaiwi Pang, President, Pacific Islander Health Partnerships Ann Duesing, Board Member, Mountain Empire Older Citizens, Inc / Mountain Laurel Cancer Resource and Support Center

Panel 2: Federal agency representatives

Ahmed Calvo, MD, MPH, Senior Medical Officer, Office of Health Information and Technology and Quality, US Department of Health Resources and Services Administration (HHS)

Lumbe Davis, MPH, Program Officer, Comprehensive Cancer Control Program

Centers for Disease Control and Prevention, DHHS

Nancy C. Lee, MD, Deputy Assistant Secretary for Health-Women's Health, Director of the Office on Women's Health (OWH), US Department of Health and Human Services (HHS)

Short break

Discussants:

Harold P. Freeman, MD, President and Founder, Ralph Lauren Center for Cancer Care and Prevention, Senior Advisor to Director of the National Cancer Institute **Tasha Tilghman-Bryant, MPA**, Manager, Strategic Initiatives

C-Change – Collaborating to Conquer Cancer

Facilitated questions and answers from the audience

11:45 AM - 12:00PM

BREAK

12:00 PM - 1:45 PM

HERBERT W. NICKENS MEMORIAL LECTURESHIP LUNCHEON

Grand Ballroom H,I,K,L

Speaker & Honoree:

David Satcher, MD, PhD, Director, The Satcher Health Leadership Institute and Center of Excellence on Health Disparities, Poussaint-Satcher-Cosby Chair in Mental Health, Morehouse School of Medicine, 16th Surgeon General of the United States

Friday, June 29



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

1:45 PM - 2:00 PM

BREAK

2:00 PM - 5:00 PM

PROFESSIONAL AND STUDENT ORAL PRESENTATIONS

Third Floor Meeting Room

2:00 PM - 5:00 PM

ICC NETWORK REGIONAL LEADERS FORUM

RESOURCES, TOOLS (TOOLKITS) AND STRATEGIES TO REDUCE HEALTH INEQUITIES

2:00 PM - 3:20 PM

DISASTER PREPAREDNESS: COMMUNITY EMPOWERMENT COMMUNITY DISASTER ALLIANCE OF NASHVILLE (CDAN)

Grand Ballroom C,F

The CDAN and its partners provide work with vulnerable populations in Nashville/Davidson County to empower them to work effectively toward being self-reliant before, during and after a disaster. CDAN provides educational opportunities in the area of disaster preparedness through trainings, seminars, workshops and distribution of literature and other materials.

3:30 PM - 5:00 PM

PATIENT NAVIGATION

Grand Ballroom C.F

Harold P. Freeman, MD, President and Founder, Ralph Lauren Center for Cancer Care and Prevention, Senior Advisor to Director of the National Cancer Institute

This session will discuss successes, barriers and key components necessary to implement and sustain patient navigation programs.

2:00 PM - 5:00 PM

CLINICAL TRIALS IN A CHRONIC DISEASE FORUM

Grand Ballroom B,E

Facilitator

James H. Powell, MD, CPI, Principal Investigator, Project I.M.P.A.C.T. (Increase Minority Awareness and Participation in Clinical Trials), a Program of the National Medical Association

Recorder: Jane Daye, MA, Program Manager, Pacific Center of Excellence in the Elimination of Disparities, Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of Hawaii

To examine what we have learned from past experiences, the panelists and participants in this session will discuss the critical need to improve collaboration between communities, clinicians and academicians in order to increase participation of minority and medically underserved populations in clinical research.

 $2:00\ PM - 5:00\ PM$

NATIONAL PARTNERSHIP FOR ACTION: REGIONAL HEALTH EQUITY COUNCILS Grand Ballroom A,D

Speaker: Rochelle Rollins, PhD, MPH, Director, Division of Policy and Data, Office of Minority Health, US HHS and Chair, Federal Interagency Health Equity Team, National Partnership for Action

The National Partnership for Action (NPA) to end health disparities is a public-private initiative that seeks to mobilize a nationwide, comprehensive, community-driven, and sustained approach to combating health disparities and to move the nation toward achieving health equity. Regional Health Equity Councils (RHEC) serve as leaders and catalysts for strengthening health equity actions within a region in response to the NPA's National Stakeholder Strategy for Achieving Health Equity.

Friday-Saturday, June 29-30



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

6:00 PM - 9:00 PM

HOPE & HEIGHT AWARDS CELEBRATION

Grand Ballroom G-L

LET'S CELEBRATE! The Height and HOPE (Helping Other People Endure) Awards will be announced and presented during a rousing reception and celebration featuring multi-cultural foods and entertainment. Please feel free to dress in attire representative of your cultural background.

Dorothy I. Height Honoree:

Marilyn Hughes Gaston, MD, Former Assistant Surgeon General and Director, Bureau of Primary Health Care, US Public Health Service Rear Admiral, USPHS, Ret., Co-Director, The Gaston and Porter Health Improvement Center

SATURDAY, JUNE 30, 2012

6:00 AM - 7:00 AM

"EXERCISE YOUR WAY TO GOOD HEALTH"

Awake with the rising sun and jump-start your day by participating in a refreshing exercise program. Get energized, rejuvenated and ready for another exciting day!

7:00 AM - 5:00 PM

REGISTRATION

7:00 AM - 8:30 AM

BREAKFAST SESSION - HAROLD P. FREEMAN LECTURESHIP

Grand Ballroom H,I,K,L

Chair:

Harold P. Freeman, MD, President and Founder, Ralph Lauren Center for Cancer Care and Prevention, Senior Advisor to Director of the National Cancer Institute

Speaker & Honoree:

Billy U. Philips, Jr., PhD, MHA, Vice President for Rural and Community Health, Texas Tech University Health Sciences Center

8:30 AM – 8:45 AM

SETTING THE STAGE FOR THE DAY

Lee Buenconsejo-Lum, MD, FAAFP, Program Chair, 25th Anniversary of the Biennial Symposium on Minorities, the Medically Underserved and Health Equity; Associate Professor, Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of Hawaii

8:45 AM - 10:15 AM

CHRONIC DISEASE PREVENTION AND CONTROL

Grand Ballroom H,J,K,L

Social Justice Concerns in Stemming the Tobacco, Diabetes and Obesity Epidemics in the Era of Obama Care

Chair:

Amber E. Bullock, MPH, CHES, Executive Vice President, Program Development, LEGACY

Sponsored by Legacy, this panel will highlight the life-saving role of preventing and controlling risk factors for chronic disease and cancer: tobacco prevention and control, community-based strategies for addressing poor diet, lack of physical activity and addressing the social determinants of health. The panelists will discuss efforts and needed strategies to ensure that chronic disease prevention becomes a sustainable reality for communities of color with health care reform, while keeping social justice issues front and center for prevention work.

Saturday, June 30



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

- "Health and Place Matters Social Determinants for Prevention"
 Marjorie A. Paloma, MPH, Senior Policy Advisor, RWJF Health Group
- "Hope & Audacity: Social Justice Prevention Perspective"
 Makani Themba-Nixon, Executive Director, Praxis Project
- "Mobilizing local, National and International Resources to Address Needs in Resource
 Limited Settings: A Reality Check"
 Neal A. Palafox, MD, MPH, Principal Investigator, Pacific Center of Excellence in the
 Elimination of Disparities Department of Family Medicine and Community Health
 John A. Burns School of Medicine, University of Hawaii
- "Strategies to Sustain the Tobacco Control Movement: Impact on Communities of Color"
 Kevin Collins, PhD, Deputy Branch Chief (Acting), Epidemiology Branch, Office of Smoking and Health, Centers for Disease Control and Prevention (CDC), US Department of Health and Human Services (HHS)

Discussant:

Dileep G. Bal, MD, MS, MPH, ICC Chair

FACILITATED DISCUSSION

SHORT BREAK

10:30 AM -12:00 PM

Continuation of Chronic Disease Prevention and Control Panel

- "Tobacco Related Disparities: Menthol Wars"
 Phillip Gardiner, DrPH, Social and Behavioral Sciences and Neurosciences and Nicotine Dependence Research Administrator for the Tobacco Related Disease Research Program (TRDRP), University of California Office of the President
- "The Obesity Epidemic Utilizing Lessons from the Tobacco Control Movement & Pearls of Wisdom From the Obesity Forefronts"
 Rod Lew, MPH, Executive Director, Asian Pacific Partners for Empowerment Advocacy and Leadership (APPEAL)
- "Diabetes Prevention and Management Among Pacific Islanders"
 Nia Aitaoto, MPH, MS, PhD (c), Principal Investigator, Faith in Action Research Alliance
- "Controlling Chronic Disease in Indigenous Populations"
 Linda Burhansstipanov, MSPH, DrPH, (Cherokee Nation of Oklahoma), Founder/President
 Native American Cancer Research Facilitated Discussion

FACILITATED DISCUSSION

12:15 PM – 2:00 PM

THE GREAT AMERICAN POSTER PICNIC

Grand Ballroom A,B,D,E

Professional, community and student poster presentations depicting research projects set in a relaxed, traditional all-American picnic environment.

2:00 PM - 3:00 PM

NON-CREDIT "HOW TO GET IN" PANEL

Grand Ballroom C,F

Moderator: Jeffrey Guidry, PhD, Associate Professor, Department of Health & Kinesiology, Texas A&M University

- Mock Interviewing (Good and Bad)
 James Phillips, MD, Senior Associate Dean and Professor of Pediatrics Office of Diversity & Community Outreach, Baylor College of Medicine
 Chester Brown, MD, PhD, Associate Professor, Department of Molecular and Human Genetics, Baylor College of Medicine
- Resume Writing/Personal Statement and Deciding Where to Apply
 Karen E. Johnson, Associate Professor, Pediatrics Newborn, Baylor College of Medicine

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Saturday, June 30



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

3:00 PM - 3:15 PM

FACILITATED DISCUSSION

Grand Ballroom C,F

3:30 PM - 4:45 PM

SOCIAL JUSTICE: RE-LIGHTING THE FIRE

Meeting Room 335 C

Panelists in this special session will challenge participants to discuss ways to mobilize minority and medically underserved communities to be effective advocates for change.

Dileep G. Bal, MD, MS, MPH, ICC Chair

Recorder: Mavis Nitta, MPH, CHES, Legacy Project Coordinator, Pacific Center of Excellence in the Elimination of Disparities, Department of Family Medicine and Community Health, University of Hawaii

3:30 PM - 4:45 PM

COMMUNITY-BASED SUCCESS STORIES Breakout sessions

Participants will have the opportunity to attend breakout sessions organized around thematic areas critical to community-based efforts to reduce health disparities. Each session will include up to 3 panelists and time for a facilitated discussion about next steps and recommendations to further the system improvements required to effect meaningful change. These recommendations will be reported to the large group on Sunday morning and will be used to guide strategic priorities for the ICC and other organizations.

Breakout sessions/focus areas:

3:30 PM - 4:45 PM

BREAKOUT SESSION: BUILDING/MAINTAINING COALITIONS - B

Meeting Room 335 A

This session will highlight successful strategies or innovative approaches used to build, rebuild or maintain active coalitions focused on control of cancer or chronic disease.

Moderator: Neal A. Palafox, MD, MPH, Principal Investigator, Pacific Center of Excellence in the Elimination of Disparities, John A. Burns School of Medicine, University of Hawaii *Recorder*: Denae W. King, PhD, Assistant Professor, The University of Texas Health Science Center at Tyler

3:30 PM - 4:45 PM

BREAKOUT SESSION: SOCIAL DETERMINANTS (HOUSING, POVERTY, EDUCATION)

Meeting Room 340 A

This session will highlight projects with demonstrated improvement in health outcomes, based on work primarily addressing reduction of poverty, improvements in education and/or the living environment.

Moderator: Carlos Gallego, MEd, Outreach Manager, Think Small, Minneapolis *Recorder:* Frankie Denise Powell, PhD, Associate Professor, School of Education, B-K Program, University of North Carolina at Pembroke

3:30 PM - 4:45 PM

BREAKOUT SESSION: PREVENTION-FOCUSED SUCCESSES

 $Meeting\,Room\,339\,A$

This session will highlight projects resulting in improvements in risk factors for developing chronic diseases, including cancer.

Saturday, June 30



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

Moderator: Celeste (CeCe) Whitewolf, JD, Native People's Circle of Hope *Recorder:* Bonnie Wheatley, MPH, MA, EdD, Vice-President, Zephyrus Group, LLC

3:30 PM - 4:45 PM

BREAKOUT SESSION: TREATMENT / ACCESS TO TREATMENT

Meeting Room 339 B

This session will highlight projects resulting in improved treatment or access to treatment for cancer or other chronic diseases.

Moderator: Sharon Barrett, MS, DrPH(c), Founder and Principal for S.E.B. and Associates *Recorder:* Kimberly Enard, PhD, RN, Postdoctoral Fellow, The University of Texas, MD Anderson Cancer Center

3:30 PM - 4:45 PM

SURVIVORSHIP MEETING

Meeting Room 340B

As cancer diagnosis and treatment have advanced, often cancer patients live for many years and have a myriad of physical and emotional issues to manage. In addition, the broad diversity of cancer survivors requires us to consider multi-cultural aspects of survivorship. This breakout session will include perspectives of researchers and community advocates regarding the issues facing diverse cancer survivors and the opportunities to address these issues.

Chair: Linda Fleisher, MPH, PhD(c), Assistant Vice President, Health Communications and Health Disparities, Fox Chase Cancer Center

Panelists:

Diana D. Jeffery, PhD, Director, Center for Healthcare Management Studies Health Program Analysis and Evaluation TRICARE, Management Activity Military Health System Assistant Secretary of Defense, Health Affairs

Westley Sholes, MPA, Vice President of Health Programs, National Association of Black County Officials

Patricia K. Bradley, PhD, RN, Associate Professor, College of Nursing, Villanova University **Kimlin Tam Ashing-Giwa, PhD,** Professor and Founding Director, Center of Community Alliance for Research and Education, Division of Population Sciences, City of Hope **Maria Guerra- Sanchez, RN, CCRP,** Tender Drops of Love

Furjen Deng, PhD, Light and Salt

6:00 PM - 6:45 PM

RECEPTION

Grand Ballroom G,J

7:00 PM - 9:00 PM

LASALLE D. LEFFALL, JR. AWARDS BANQUET & GALA

Grand Ballroom H,I,K,L

Recognizes individuals and organizations that have distinguished themselves in addressing the cancer crisis in minority and medically underserved communities through educational programs, clinical service, research, or public awareness.

HONOREE

Neal A. Palafox, MD, MPH, Principal Investigator, Pacific Center of Excellence in the Elimination of Disparities, Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of Hawaii

Saturday, June 30 - Sunday, July 1



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

LEAP OF FAITH AWARD

The Leap of Faith award recognizes an organization and/or individual who has come forward at critical moments to support the mission, ideas and efforts of the Biennial Symposium Series and/or the Intercultural Cancer Council.

Honoree:

University of Houston, accepting on behalf of the university **John Antel, PhD,** Provost and Senior Vice President

SUNDAY, JULY 1, 2012

6:00 AM – 7:00 AM "EXERCISE YOUR WAY TO GOOD HEALTH"

Awake with the rising sun and jump-start your day by participating in a refreshing exercise program. Get energized, rejuvenated and ready for another exciting day!

7:30 AM - 9:00 AM **CONTINENTAL BREAKFAST**

Grand Ballroom Pre Function Area G

7:45 AM – 8:00 AM **SETTING THE STAGE FOR THE DAY**

Grand Ballroom H,I,K,L

Lovell A. Jones PhD, Director and Professor, Center for Health Equity & Evaluation Research, The University of Texas MD Anderson Cancer Center/University of Houston

8:00 AM – 9:45 AM **CAPACITY BUILDING WORKSHOPS**

Participants will be able to select one of several concurrent workshops designed to transmit information and/or skills that can be utilized in community-based work aimed at reducing health inequity.

8:00 AM - 9:45 AM

WORKSHOP: ESTABLISHING, IMPLEMENTING AND MAINTAINING AN ACADEMIC-COMMUNITY PARTNERSHIP: ETHICAL CONSIDERATIONS

Meeting Room 336 A&B

Chair: Jean Ford, MD, Director, Johns Hopkins Center to Reduce Cancer Disparities

Contemporary IRB guidelines address key ethical principles in the protection of individual research participants, including autonomy, beneficence, nonmaleficence and justice. However, the guidelines are relatively under-developed when it comes to protecting communities engaged in community-based participatory research (CBPR) against potential adverse consequences of that research. This workshop will explore ethical challenges in CBPR, and discuss potential solutions from the perspectives of community-engaged researchers and academically-engaged community members.

Presenters:

Chanita Hughes Halbert, PhD, Professor, Department of Psychiatry and Behavioral Sciences, Medical University of South Carolina

Bettina Drake, PhD, Assistant Professor, Division of Public Health Sciences, Dept. of Surgery, Siteman Cancer Center, Washington University School of Medicine

Michele Towson, JD, Director of Grant Development, Baltimore Community College

8:00 AM – 9:45 AM WORKSHOP: APPROACHES TO GRANT WRITING

Meeting Room 338



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY **UNDERSERVED & HEALTH EQUITY**

Empowering Communities in the Era of Health Care Reform

This workshop will review the basics of writing grant proposals and getting them funded. Topics will include needs assessment, project development, budgeting, finding funders, and general "grantsmanship" skills. The focus includes both community-based organizations and academic researchers interested in research as well as "practical" demonstration projects. Participants will also receive an extensive list of resources for additional background and continued networking after the workshop.

Presenter: Larry Laufman, EdD, Assistant Professor, Baylor College of Medicine,

8:00 AM - 9:45 AM

WORKSHOP: COLLABORATION TO ADDRESS CHRONIC DISEASES

Meeting Room 337 A

This workshop will share strategies, tips and tools useful to community coalitions working to address chronic diseases. The presenter will share specific approaches to working with chronic disease partners to achieve common goals, tips and tools for collaborative planning, sharing data, and coordinating work among common partners and populations.

Presenter: Karin Hohman, RN, MPH, President, Strategic Health Concepts

8:00 AM - 9:45 AM

WORKSHOP: ADVOCACY 101

Meeting Room 327

This workshop will explore the basics of how to be an advocate and how important this work can be; it will also help participants understand how important they can be in furthering good health at the local, state and federal levels.

Presenters:

Jennie Cook and Citseko Staples Miller, American Cancer Society Cancer Action Network

Jackie Young, PhD, Chief Staff Officer, High Plains Division, Hawaii Pacific, American Cancer Society, Inc.

8:00 AM - 9:45 AM

WORKSHOP: MEDIA ADVOCACY

Meeting Room 328

The Media Advocacy workshop will help advocates learn to engage the news media strategically. Whether the goal is increasing funding and support for community-based programs or advocating for more linguistically and culturally-appropriate access to health services, participants can harness the power of the news media to amplify their voices, reach policy-makers, and advance their policy goals.

Presenters: Trish Quema, Roxanna Bautista, MPH and Pedro Arista

Asian & Pacific Islanders American Health Forum (APIAHF)

8:00 AM - 9:45 AM

WORKSHOP: PROJECT SECURE: DISASTER PREPAREDNESS

Meeting Room 329

This workshop will feature community-based applications of selected findings from the SECURE RESEARCH CONSORTIUM in the context of Health Reform. The overall goal of the workshop is to examine the relationship between health reform and disaster management and the impact on at-risk communities. Presenters will focus on four interdependent questions: (1) What is the anticipated impact of Health Reform on disaster recovery in Gulf Coast communities? (2) How can we use available health data to predict the need for health services for those with a chronic disease burden during and after a disaster? (3) What are examples of evidence-based practice to strengthen community preparedness? and (4) How can schools play a role in advancing family readiness?



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

Presenters:

Patricia Matthews-Juarez, PhD, Associate Vice President, Faculty Affairs and Development, Professor Family and Community Medicine, Meharry Medical College

Maureen Lichtveld, MD, MPH, Freeport McMoRan Chair of Environmental Policy, Department of Environmental Health Sciences, Tulane University School of Public Health and Tropical Medicine

Alexandra (Lexi) B. Nolen, PhD, MPH, Director of Health Policy and Planning, Center to Eliminate Health Disparities, Associate Director, UTMB PAHO/WHO Collaborating Center for Training in International Health, Assistant Professor, Department of Family Medicine, The University of Texas Medical Branch Galveston

John Prochaska, DrPH, MPH, Program Manager, Assistant Professor, UTMB's Dept of Preventive Medicine and Community Health (PMCH), University of Texas Medical Branch Galveston

Faith Foreman, PhD, Assistant Director City of Houston, Dept. of Health and Human Services

8:00 AM - 9:45 AM

WORKSHOP: COMPREHENSIVE CANCER CONTROL COALITION EFFORTS TO ENGAGE DIVERSE COMMUNITY PARTNERS

Meeting Room 330

Comprehensive cancer control succeeds when communities and coalitions work together to address common cancer issues. This session will identify ways to bring together community partners and cancer coalitions to engage in collaborative efforts. We will share successful approaches to common challenges such as shared decision making, identifying resources and managing implementation.

Presenter: Leslie Given, MPA, Vice President, Strategic Health Concepts

8:00 AM - 9:45 AM

WORKSHOP: WHAT ARE CANCER CLINICAL TRIALS AND WHY SHOULD COMMUNITIES CARE?

Meeting Room 332

This workshop is designed to introduce the topic of cancer clinical trials to community members and cover key facts about how trials work and why they are important in advancing progress in cancer care. The workshop will address many of the common myths and misconceptions about cancer clinical trials and discuss ways to find out more about studies available in local communities.

Presenters: Margo Michaels, MPH, Executive Director, Education Network to Advance Cancer Clinical Trials (ENACCT)

8:00 AM - 9:45 AM

WORKSHOP: MAKING DATA TALK: COMMUNICATING PUBLIC HEALTH DATA Meeting Room 333

Programs need to present data to make the cancer control case to the public, media, and policy makers. However, communicating data and other scientific information to lay audiences can be difficult. It is critical to understand the totality of communication processes in public health, the many factors that influence it, and the importance of data selection and presentation. This workshop reviews communication concepts, provides recommendations on selecting and presenting data, and introduces an easy to understand framework for communicating data. Participants will receive a workbook that will be used during the workshop that will help reinforce key concepts and provide examples.

Presenter: Harry Kwon, PhD, MPH, MCHES, Office of Communications and Education National Cancer Institute (NCI)



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8:00 AM - 9:45 AM

WORKSHOP: INTRODUCTION OF ONLINE CONTINUING EDUCATION PROGRAM, "ACCESS TO CANCER CARE FOR LOW-INCOME AND UNINSURED PATIENTS"
Meeting Room 339 A

This workshop will focus on the impact and care issues of health disparities that exist in underserved populations in Texas and resources that are available in obtaining quality healthcare services for those populations.

Presenter: Lewis Foxhall, MD, Office of Health Policy, The University of Texas MD Anderson Cancer Center

8:00 AM - 9:45 AM

WORKSHOP: TRANSLATING EVIDENCE INTO PRACTICE: USING WHAT WORKS Meeting Room 339 B

Many grants require applicants to use "evidence-based" programs. What does that mean and how do you do it? In this session, we will briefly cover levels of evidence and where to find evidence-based programs and strategies. We will spend the majority of the session discussing how to select strategies to fit an organization and its project objectives. We'll put these planning steps into practice through small group exercises

Presenters:

Maria Fernandez, PhD, Associate Professor of Health Promotion and Behavioral Sciences, The University of Texas School of Public Health

Linda Civallero, MPH, Center for Community-Engaged Translational Research, The University of Texas MD Anderson Cancer Center

8:00 AM - 9:45 AM

WORKSHOP: USE OF SOCIAL MEDIA TO DO COMMUNITY WORK Meeting Room $340\,A$

This workshop will examine how the use of social medial platforms, like Facebook, Twitter, and blogging can be used to educate, empower, and bring positive changes to communities.

Presenters:

Genma Holmes, Radio Host, Living Your Best Life Now **Shawn P. Williams,** Publisher and Editor-in-Chief, Dallas South News **Jody Schoger,** Columnist, OncologyTimes, Co-Founder, "BreastCancerSocialMedia"

8:00 AM - 9:45 AM

WORKSHOP: USING MULTI-SECTOR COLLABORATION TO ADDRESS DISPARITIES ACROSS THE CONTINUUM OF CANCER RESEARCH, PREVENTION AND CARE Meeting Room 340 B

Participants at this workshop will be provided with an overview of C-Change's multi-sector approach to its six strategic initiatives – Patient Privacy & Cancer Research (HIPAA), Cancer Risk Reduction, Cancer Health Disparities, Cancer Workforce, Value in Cancer Care, and Comprehensive Cancer Control. Each initiative incorporates aspects of cancer health disparities, vulnerable communities, and/or underrepresented professionals. A panel of C-Change members will outline strategies employed, highlight available materials and tools developed by C-Change, and describe how these resources can be used to establish similar cancer control initiatives in communities throughout the country.

Presenters:

Tasha Tilghman-Bryant, MPA, C-Change

Maureen Lichtveld, MD, MPH, Freeport McMoRan Chair of Environmental Policy, Department of Environmental Health Sciences, Tulane University School of Public Health and Tropical Medicine



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

9:45: AM – 10:00 AM **BREAK**

3rd Floor Pre Function Area

10:00 AM – 11:15 AM **PLENARY SESSION**

Grand Ballroom H,I,K,L

10:00 AM – 10:45 AM **VOICES FROM THE COMMUNITY:**

Report out from the community breakout sessions on priority areas

Lee Buenconsejo-Lum MD, FAAFP, Program Chair, 25th Anniversary of the Biennial Symposium on Minorities, the Medically Underserved and Health Equity, Associate Professor, Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of Hawaii

10:45 AM – 11:15 AM **REFLECTIONS AND NEXT STEPS:**

Honorary Chairs:

Charles A. LeMaistre, MD, Former President, The University of Texas MD Anderson Cancer Center

and Former Chancellor, The University of Texas

Pamela M. Jackson, MS, Interim Executive Director, Intercultural Cancer Council

Betty Lee Hawks, MA, Former Special Assistant to the Director, Office of Minority Health,

Department of Health and Human Services; APPEAL Board Chair

Harold P. Freeman, MD, President and Founder, Ralph Lauren Center for Cancer Care and

Prevention, Senior Advisor to Director of the National Cancer Institute

Dileep G. Bal, MD, MS, MPH, ICC Chair

11:15 AM – 11:30 AM **BREAK**

11:30 AM – 1:00 PM FAREWELL JAZZ BRUNCH - MAJOR KEYNOTE SPEAKER

Grand Ballroom H,I,K,L

1:00 PM **EVALUATION AND ADJOURNMENT**



BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

WEDNESDAY, JUNE 27, 2012

FOUNDER'S AWARD RECEPTION

6:30 PM – 8:30 PM *Grand Ballroom H,I,K,L*

Honoree:

Sandral Hullett, MD, MPH, CEO & Medical Director, Cooper Green Hospital

THURSDAY, JUNE 28, 2012

SUSAN MATSUKO SHINAGAWA LIVESTRONG CANCER CONTROL LEADERSHIP AWARD LUNCHEON

12:00 PM - 1:45 PM *Grand Ballroom H,I,K,L*

Speaker:

Robert G. Robinson, MSW, DrPH, Association Director Emeritus, Public Health Consultant, Health Power Editor, Smoking and Health, and Race, Culture and Health

Honorees:

COL (Ret.) James E. Williams, Jr., MS, SPHR, ICC Immediate Past Chair

Olga G. Sánchez, Community Health Program Representative, Moores Cancer Center, University of California, San Diego

FRIDAY, JUNE 29, 2012

HERBERT W. NICKENS MEMORIAL LECTURESHIP LUNCHEON

12:00 PM - 1:45 PM

Grand Ballroom H,I,K,L

Speaker & Honoree:

David Satcher, MD, PhD, Director, The Satcher Health Leadership Institute and Center of Excellence on Health Disparities, Poussaint-Satcher-Cosby Chair in Mental Health, Morehouse School of Medicine, 16th Surgeon General of the United States

HEIGHT AND HOPE AWARDS CELEBRATION

6:00 PM - 9:00 PM

Grand Ballroom G-L

Dorothy I. Height Honoree:

Marilyn Hughes Gaston, MD, Former Assistant Surgeon General and Director, Bureau of Primary Health Care, US Public Health Service, Rear Admiral, USPHS, Ret., Co-Director, The Gaston and Porter Health Improvement Center

SATURDAY, JUNE 30, 2012

HAROLD P. FREEMAN LECTURESHIP

7:00 AM – 8:30 AM

Grand Ballroom H,I,K,L

Speaker & Honoree:

Billy U. Philips, Jr., PhD, MHA, Vice President for Rural and Community Health, Texas Tech University Health Sciences Center

THE GREAT AMERICAN POSTER PICNIC

12:15 PM - 2:00 PM

Grand Ballroom A,B,D,E

LASALLE D. LEFFALL, JR. AWARDS BANQUET & GALA

7:00 PM - 9:00 PM

Grand Ballroom G-L

Honoree:

Neal A. Palafox, MD, MPH

Principal Investigator, Pacific Center of Excellence in the Elimination of Disparities, Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of Hawaii

LEAP OF FAITH AWARD

Honoree

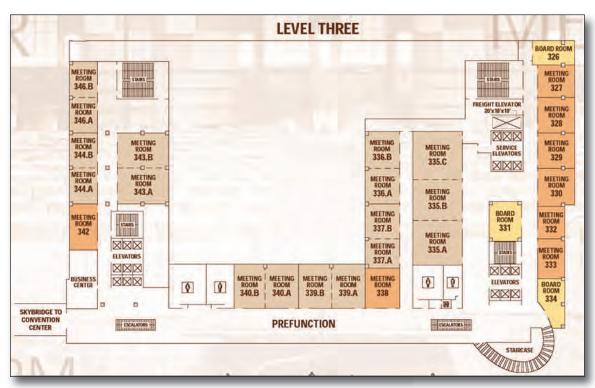
John Antel, PhD, Provost and Senior Vice President, University of Houston

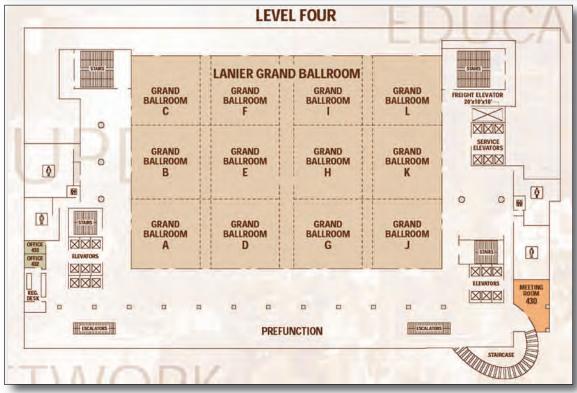
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BIENNIAL SYMPOSIUM ON MINORITIES, THE MEDICALLY UNDERSERVED & HEALTH EQUITY

Empowering Communities in the Era of Health Care Reform

HILTON AMERICAS HOTEL







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FINAL REPOORT 119



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National Minority Cancer Awareness Week Luncheon

The Dorothy I. Height Center for Health Equity & Evaluation Research (DH-CHEER) celebrated the National Minority Cancer Awareness Week (NMCAW), April 15-21, 2012. In celebration of NMCAW's 12th Annual Luncheon, DH-CHEER partnered with The University of Texas' McGovern Center for Humanities and Ethics to feature guest speaker Jay Moskowitz, PhD on April 18, 2012. Dr. Moskowitz discussed the significance and advantages of developing a strategic model to transform public health and economic well-being through research. He has over 40 years of experience in the field of biomedical research and the President/CEO of the Health Sciences South Carolina (HSSC), the nation's only statewide biomedical research collaborative.



<u>Jay Moskowitz, Ph.D.</u>

Speaker: James B. Duke SmartState Endowed Chair

Professor of Translational Clinical Research at the University of South Carolina

President and CEO of Health Sciences South Carolina

DH-CHEER's annual luncheon symposium honors scientists, community members whose work aim at reducing cancer and health disparities in minority populations. The event also feature distinguished guest speakers and experts in the areas of public health, cancer, research, and social sciences. Previous keynote speakers include U.S. Surgeon Generals, Drs. David Satcher and Joycelyn Elders; former Commissioner of the Texas Department of State Health Services, Dr. Eduardo Sanchez; President and Chancellor of the University of Houston, Dr. Renu Khator, and Executive Vice Chancellor for Health Affairs of The University of Texas System and the former President of the Institute of Medicine (IOM), Dr. Kenneth Shine, and Drs. William Jenkins and Stephen Klineberg.

Event Flyer in PDF

Upcoming: DH-CHEER will host a lectureship in recognition of National Minority Cancer Awareness Week 2013. More information to follow.

History of National Minority Cancer Awareness Week

In 1986, Lovell A. Jones, Ph.D., approached Senator Lloyd Bentsen and Representative Mervyn Dymally to support a joint resolution to designate the full third week in April as National Minority Cancer Awareness Week. On April 8, 1987, the U.S. House of Representatives' Joint Resolution 119 designated the full third week in April as *National Minority Cancer Awareness Week*. As explained in the Congressional Record, Resolution 119 drew attention to "an unfortunate, but extremely important fact about cancer. While cancer affects men and women of every age, race, ethnic background and economic class, the disease has a disproportionately severe impact on minorities and the economically disadvantaged."

As the first Congressionally mandated minority health research center outside of the federal government, DH-CHEER has taken the leading role in addressing this issue. National Minority Cancer Awareness Week promotes increased awareness of prevention and treatment among those populations at greater risk of developing cancer. The week's emphasis gives health care professionals and researchers an opportunity to focus on high-risk populations. The goal is to develop creative approaches to address the needs in these unique communities.

GRANTETAYLOR LECTURESHIP

McGovern Center for Humanities and Ethics

and

Center for Health Equity and Evaluation Research

Lecture: Health Sciences South Carolina -The Nation's First Statewide Biomedical Research Collaborative

Meet Dr. Moskowitz..... James B. Duke SmartState Endowed Chair, Professor of Translational Clinical Research at the University of South Carolina and President and CEO of Health Sciences South Carolina (HSSC)

Dr. Moskowitz has over 40 years in the field of biomedical research. The HSSC is the nation's only statewide biomedical research collaborative committed to transforming South Carolina's public health and economic well-being through research. Understanding the significance of partnerships, strategic alliances were formed with the South Carolina Hospital Association, the South Carolina Medical Association, The Duke Endowment, the South Carolina SmartState™ Program, and Siemens Medical. Under the leadership of Dr. Moskowitz, the HSSC brings a unique perspective and approach to research with a more implementation-centered approach to improve patient care and population health. The mission of the HSSC is to conduct collaborative health sciences research to improve the health status, education, workforce development, and economic well-being for all South Carolinians.

Mr. Moskowitz began his career at the National Institutes of Health (NIH), rising to the positions of Principal Deputy Director and Deputy Director for Science Policy and Technology Transfer in the Office of the Director. In 1989, Dr. Moskowitz was selected as the Founding and Interim Director of the National Institute on Deafness and Other Communication Disorders. In 1995, he was recruited by Wake Forest University School of Medicine where he served as Senior Associate Dean for Science and Technology. He played an instrumental role in the enhancement of their research mission and the development of Wake Forest's Downtown Research Park. Dr. Moskowitz also served as a Professor of Medicine in the College of Medicine and Professor of Health Policy and Administration in the College of Health and Human Development at Penn State.





Dr. Jay Moskowitz

James B. Duke SmartState Endowed Chair

Professor of Translational Clinical Research at the University of South Carolina

President and CEO of Health Sciences South Carolina



12 NOON, Wednesday, April 18th, 2012

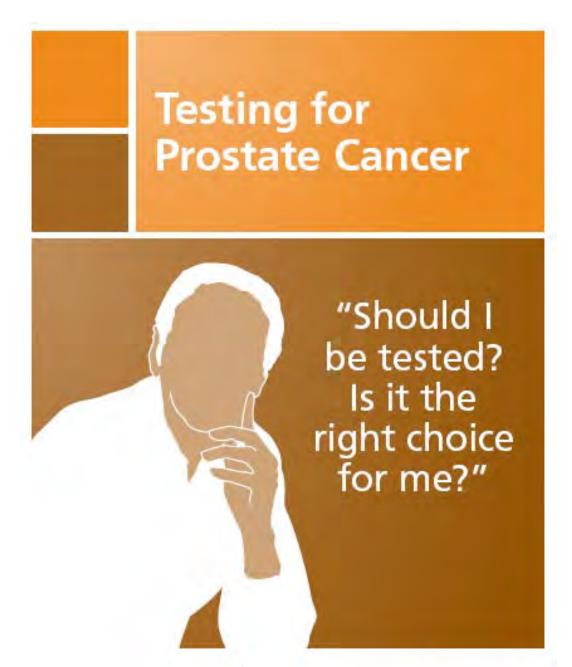
MD Anderson Cancer Center Basic Science Research Building Onstead Auditorium (S3.8012) 6767 Bertner Houston, TX 77030-2603



- LUNCH and PARKING validation provided for the first 100 attendees
- Parking validation provided ONLY for the John P. McGovern Texas Medical Center Commons Garage at 6550 Bertner Avenue (just past the huge Wall Waterfall)
- For additional information, please call 713-745-1774

CRMH Peer-Reviewed Publications 2011 - 2013

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- 2. Omojasola A, Hernandez M, Sansgiry SS, Paxton R, Jones L. Federally qualified Health Center Patients and Generic Drug Discount Programs. J Health Care Poor Underserved 23(1):358-66, 2/2012.
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This information will help you decide if you want to be tested for prostate cancer.





- There may be both benefits and risks with prostate cancer testing and treatment.
- Research has not yet proven that the benefits outweigh the risks.



- Here we will talk more about prostate cancer and the possible benefits and risks of testing and treatment.
- After viewing this slide show we hope you will be able to decide if you would like to be tested.
- If you have additional questions please talk to your doctor or ask the medical counselor on site.



The information in this slide show is to help men who do not have any prostate symptoms decide if they want to be tested.

You should talk with a doctor right away if you have:

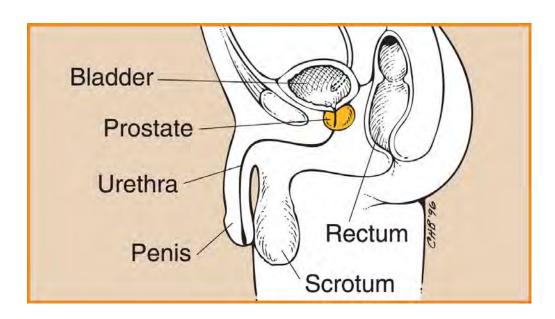
- trouble passing urine,
- blood in your urine, or
- pain when you pass your urine

These are often symptoms of other prostate problems, but they can also be caused by prostate cancer. The only way to know what is wrong is to see a doctor.

About prostate cancer

What is prostate cancer?

- Cancer begins in your body when normal cells start
- to grow out of control.
- In prostate cancer, prostate cells grow out of control.
- Cancer cells can spread and affect nearby organs. They can also spread to distant parts of the body and cause problems.





Are all prostate cancers the same?

Prostate cancer can cause death. But not all prostate cancers are the same.

- Many prostate cancers grow slowly. These do not usually cause any harm.
- Some prostate cancers grow fast. They can spread to other parts of the body where they cause severe pain and other problems, and can even cause death.



What are my chances of having prostate cancer?

17 out of 100 men (17%) age 50 will be diagnosed with prostate cancer during their life.



- = man not diagnosed with prostate cancer
- = man with prostate cancer



What are my chances of dying of prostate cancer?

3 out of 100 men (3%) age 50 will some day die of prostate cancer.







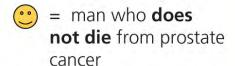












= man who **dies** from prostate cancer



A **PSA blood test** and **rectal exam** can tell your doctor about your prostate.

PSA stands for **Prostate Specific Antigen**.

- PSA is a protein made by the prostate gland.
- The PSA test measures how much of this protein is in your blood.
- It is done by having a small amount of blood taken from a vein in your arm.



Rectal exam

- The doctor puts a gloved, lubricated finger into your rectum to feel your prostate gland.
- A rectal exam can tell if the prostate size, shape, and texture are normal.





No. There is no perfect test to look for prostate cancer.



Rectal exam

- If your rectal exam does not suggest cancer, you can still have prostate cancer.
- Most cancers cannot be felt by rectal exam.
- But sometimes rectal exams can find cancer even when the PSA level does not suggest cancer.



PSA Test

There is no PSA level that says for sure that prostate cancer is present or is not present.

- PSA levels can be low when cancer is present.
- Your chance of having prostate cancer goes up as your PSA level goes up.
- PSA levels can be high in prostate cancer, and also with prostate infections and other prostate problems.
 So, having a high PSA level does NOT always mean that you have prostate cancer.

If your PSA level is high, you will need other tests to find out why.

How do I find out if I have prostate cancer?



If your PSA level or your rectal exam suggests cancer, you may need a **biopsy** of your prostate gland.

- A biopsy is done with a needle.
- Many tiny pieces of the prostate gland are removed.
- These tiny pieces are looked at under a microscope to look for cancer cells.
- The biopsy is done as an outpatient and takes only about an hour.

What is my chance of having prostate cancer based on my PSA level?

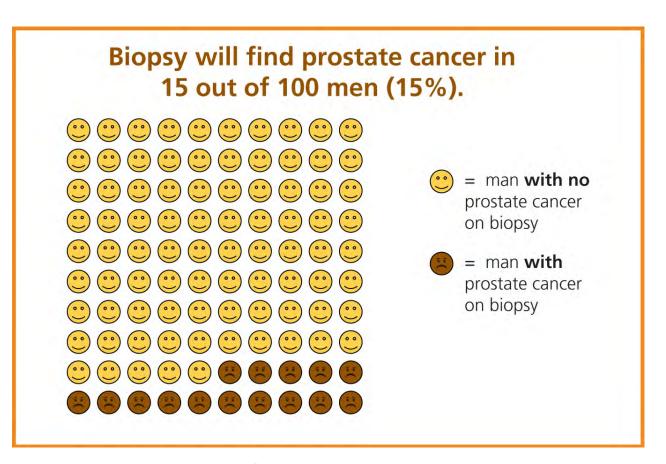
If the PSA level is 4 or higher:

Biopsy will find prostate cancer in 30 out of 100 men (30%).

- = man with no prostate cancer on biopsy
- = man with prostate cancer on biopsy

What is my chance of having prostate cancer based on my PSA level?

If the PSA level is **below 4**:





You get a PSA test and maybe a rectal exam.

If your test results are cause for concern, you have a biopsy.

Possible benefits if you get tested

- Testing may find an early prostate cancer while it is small and before it has spread.
- If it is found early, there is a better chance of being treated and cured.
- You may avoid pain and suffering from cancer.
- Getting tested may give you peace of mind.



Possible risks if you get tested

- Your PSA level may be low, even though cancer is there.
- You may worry about the results.
- Testing may find a cancer that might never have caused you any problems.
- Testing may lead to side effects from treatment.
 These include problems controlling your urine,
 problems with your bowels, and/or problems having sex.



You have regular check-ups but no prostate cancer testing.

You can change your mind and be tested in the future.

Possible benefits if you do not get tested

- You avoid the worry that you might have from testing.
- You avoid being treated for a cancer that might never cause you any problems.
- You avoid the side effects that can occur with treatment.



Possible risks if you do not get tested

- You may have an early prostate cancer, and you won't know this.
- You may have a prostate cancer that will later cause symptoms or shorten your life, and not have the chance to find it early.

How do you decide if testing is the right choice for you?

Weigh your options and decide what is important to you.

There are many reasons men decide to be tested or to not be tested for prostate cancer.

Some reasons are listed on the next slide.

Think about which of these reasons are important to you.



So What's Important to You?

Some reasons a man may choose to be tested	Some reasons a man may choose not to be tested
I will have peace of mind when I know the test results.	I will worry about the test results.
I will know if I have prostate cancer or not.	I might find a prostate cancer that never would have caused problems or shortened my life.
I will have a better chance of getting cancer treatment if a cancer is found early.	If cancer is found I might have to deal with treatment and side effects.



Talk to a doctor or medical counselor about prostate cancer testing and treatment.

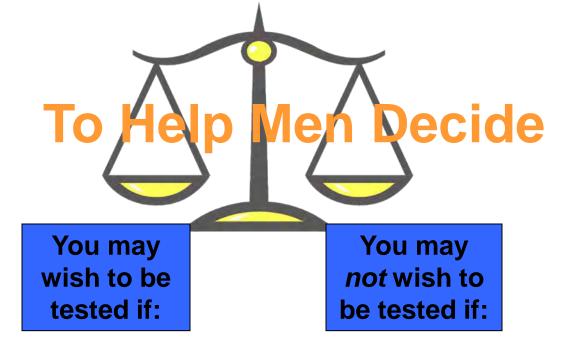
- You should think through the risks and possible benefits;
- Think about what is important to you;
- Then you should decide if testing is the right choice for you.



If you are African American or have a father or brother who had prostate cancer before age 65, have this talk with your doctor starting at age 45.

Men with 2 or more close relatives who had prostate cancer at an early age should have this talk starting at age 40.

If you decide to be tested, you should have the PSA blood test with or without a rectal exam. How often you are tested will depend on your PSA level.



- You value finding cancer early
- You are willing to be treated without definite benefit
- You are willing to risk urinary, sexual, or bowel injury from treating early prostate cancer
- You place a higher value on avoiding the risks of screening & treatment, such as worry or problems with urinary, sexual, or bowel function
- You are willing to accept the chance that you may have prostate cancer and not know about it before it causes you harm

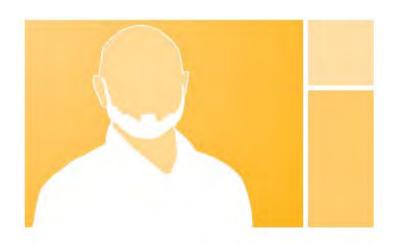
The decision is yours

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- American Cancer Society
 - **-** 1-800-227-2345
 - www.cancer.org/prostatemd
- U.S. Centers for Disease Control and Prevention
- Mayo Clinic
- Foundation for Informed Medical Decision Making

For cancer information, answers, and support, call your American Cancer Society 24 hours a day, 7 days a week at 1-800-227-2345.



Questions?



ACS Findings & Quotes of the Prostate Cancer Testing Booklet – Spanish Version Disposition Report

Based on Conference Call: December 13, 2011 Attendees: Dr. Durado Brooks, Terri Ades (ACS) Dr. Robert Volk (MDACC) Members of ACS reported observations and finding of a Spanish translated version of the aid conducted by ACS and slide-set summary was distributed. Below are further findings, recommendations, suggestions, etc. we can make/improve moving forward.

Some observations from testing results were taken from conference call minutes from Dr. Volk, Dr. Brooks & Terri Ades.

- An 18 page booklet was tested: Testing for Prostate Cancer
 - Only a few participants were able to read through the whole booklet during the interview sessions
- The booklet tested was a direct translation of the English version
- Participant Profiles
 - 20 Unacculturated, 5 Bicultural
 - Ages ranged from 40-64 (average of 56)
 - 18 high school or less 7 college educated
 - Participant representations of different household incomes, from \$15K to \$100K
 - Tenure living in the US ranged from 6 to 56 years (average of 28 years)
 - 11 from Mexico
 - 14 from other countries: Columbia (5), Puerto Rico (3), El Salvador (2), Argentina, Cuba, Guatemala and Panama (Overall the Mexican participants – with few exceptions – were the less educated)

- Twenty 55-minute in-depth interviews
 - Hispanic males
 - Each participant was given 10 minutes to review the booklet in private, without interruption
- All interviews were conducted in Spanish
- The main goal was to evaluate the reaction and call to action of the booklet and its contents by the Hispanic target audience.
- Other objectives included:
 - To evaluate overall reactions to the booklet and its relevancy
 - To identify areas of interest or lack thereof of the booklet as well as areas that they don't understand or need additional explanations.
 - To determine the action(s) to be taken once they read the booklet
 - To evaluate the quality of the Spanish language used for ease of understanding the topics.
 - Understand attitudes about preventive care
 - Understand beliefs, attitudes and perceptions about PC and PC screening
 - Understand the image and perceptions of the ACS

- Less than half of the participants had insurance provided by their employer
- Those that do not have insurance only go to the doctor when they have a problem, emergency or a persistent condition
- Some of those without insurance go to their home country to be treated either because it is cheaper or because they still maintain some type of insurance
- Other search for health care clinics or hospitals that provide assistance at a low price or pay for treatment based on income
- Most that have insurance take advantage of having themselves checked by the doctor periodically but not all of them have a PC exam conducted periodically or a few of them never
- For those that have PC testing, they don't necessarily go over the details of the tests themselves
 - I just want to know if I pass the test, or not.

 The Doctor will tell me what I need to know."
 - I'm not a Doctor. I am going to do the test if my Doctor tells me to. It's not up to me.

Problem / Issue Identified	Description	Strategy	Disposition
Only 3 out of 25 participants fully understood the question on the cover of the booklet ('Should I be tested? Is it the right choice for me?')- and the purpose of the booklet - a guide that provides PC information - to make a final decision considering both alternatives either to do PC testing or not.	Cover of the Booklet: The phrase "Should I" translated as "Debo" which in Spanish could be interpreted as "Must I"	Should change: "¿Debo hacerme las pruebas?" to "¿Debería hacerme las pruebas? Also suggest: instead of having "Is it the right decision for me?" on the cover, say "The decision is mine" "La decision es mía."	Changed "debo to "debería". The second "thought" is now a statement – not a question. "The decision is mine" "La decision es mía."
In other words, 22 of the 25 respondents believed that the call to action was to encourage them to go to the doctor for a PC test – most of these individuals expect an organization, such as the ACS, to give them "the push" to be tested. Because any type of cancer is a serious matter, for most of them, the answer is to have the courage to take action, and easily rationalize that the call to action is to encourage them to be tested.	Message of the Booklet: Booklet Comprehension	Slight modifications and editing will be necessary to ensure that the call to action is clear Page 7 of ACS PCDA Slide-set presents the message early on and more clearly than in the booklet. "La decision es suya"—"The decision is yours." Is repeated throughout the slide-set.	Although this is not applicable for the slideset, the modification mentioned above, should assist to drive the message that they choice is theirs.
Participants appreciate the effort by the ACS, and see them as an authority to communicate and educate about cancer in the US, and look to them first for help to take action and them to educate them about what they do not know.	Message of the Booklet: Participant Perception of ACS	N/A	N/A
Some participants were aware or had heard of the ACS. They claimed that most of their awareness comes from advertisement, public service announcement or otherwise. Few mentioned that they know of the ACS when they attend health fairs or when they obtain healthcare literature.	Message of the Booklet: Participant Perception of ACS	N/A	N/A

Problem / Issue Identified	Description	Strategy	Disposition
Participant image of the ACS is positive in their mind, they feel it is reputable, credible, an authority in communicating and educating about all type of cancer and they perceive ACS to be a non-profit organization with good objectives and noble – and for this reason the ACS must be highly commended.	Message of the Booklet: Participant Perception of ACS	N/A	N/A
All participants perceived the booklet to have value, provide information about a topic they know very little to nothing about as well as new information to be better prepared to ask questions to the doctor when they see them.	Message of the Booklet: Overall Impression of Booklet	Although participants felt the booklet helped them to better understand PC and PC testing, modifications and editing will be necessary to ensure the call to action is clear. Page 7 of ACS PCDA Final Report Addressed above.	Addressed above.
Several men noted that people in their culture "do not like to read" - booklet perceived to be too lengthy and text heavy. "If the purpose of this booklet is to go to the average Hispanic males I know the cover needs to be more dramatic, have more of an attention grabber. To begin with, Hispanics don't like to read, that is a known fact, so the cover needs to hit them. Believe me, we are not like the Americans that are calm and collected and like to read."	Message of the Booklet: Overall Design	The majority of Spanish-speaking men in the U.S. are of average to below average education; therefore communications need to be kept simple for ease of understanding. The booklet also seemed to have too much information. Consideration should be given to cut the length of the booklet. Page 8 of ACS PCDA Final Report Page 38 of ACS PCDA Final Report	Information will be presented by a health educator via the slide-set, no need for participants to read a booklet in our version. Furthermore, the slides break up information to make it simpler to understand.

Problem / Issue Identified	Description	Strategy	Disposition
It was clearly understood that the topic Prostate Cancer Testing	Cover of the Booklet: Header	The cover of the booklet makes a statement and poses a question that the person should ask himself, perhaps a statement of action should be added e.g. 'This booklet will help you make an informed decision' Page 41 of ACS PCDA Test messages that will ensure that the slide-set is clearly understood.	For testing, we are adding this statement "Esta information le ayudará a decider si usted quiere hacerse las pruebas de detección de cancer de próstata." at the end of page 2 of the slides "This information will help you decide if you want to be tested for prostate cancer."
Some participants recommend the inclusion of a stronger attention grabber in the header (e.g. the number of men that are diagnosed with Prostate Cancer per year) Although some of this information is discussed in a latter portion of the booklet, many participants did not read that far into the booklet or finish reading the booklet.	Cover of the Booklet:	We won't use the "attention grabber" since this is not trying to convince people to be screened (as the men thought). N/A	N/A
Recommendations were made with regards to the translation of the ACS Tagline 'The Official Sponsor of Birthdays'	Cover & Back Cover of Booklet: Translation	Recommended translation 'Para que cumplas muchos más años' Page 19 of ACS PCDA Final Report We will keep this as is, and ask participants what they think about it.	N/A

Problem / Issue Identified	Description	Strategy	Disposition
Participants that had time to read, liked the content of the back cover. The amount of text, language and simplicity, was clear and made sense to them. "This information is great, concise and easily understood. Actually this section should be at the front, this way people really know what this booklet is all about." "This information is great. It really should be	Back Cover of Booklet: Comprehension / Clarification	Some participants suggested that this section should be included as part of the intro of the booklet or as part of the header as an attention grabber. Page 29 of ACS PCDA Final Report Consider putting this all up front as the second slide – overview?	This was not relevant with the slide-set. N/A
Participants claimed that clarification is needed as far as the information they can obtain by calling the telephone number listed. Some participants believed the number listed is one that can refer them to a doctor or location where they can get a PC test, when in fact it is a number they can call to get additional information about PC testing. Also, specifications on time would need to be made with regards to call time (the translation states to call during office hours, which lead the questioner to wonder what those are), when in fact they can call at any time.	Back Cover of Booklet: Comprehension / Clarification	Specify that they can all anytime and what type if information will be provided when calling this number; also, making certain to communicate that this is a bilingual service is important as well. Page 41of ACS PCDA Final Report Slide is clear at the top that number is for help to make a decision, but later says it's for "information about cancer, questions and support." Per ACS is not for referral to doctor or location to get a PSA. Need to clarify if the Spanish line is actually available 24/7 as stated since in English booklet since the Spanish booklet says to	Suggest a list of the websites for the organizations and phone number for help (from the information on the slide) – provided that these are given as a handout. If not, suggest removing all other phone number (other than ACS).

Problem / Issue Identified	Description	Strategy	Disposition
Although some liked the faceless image, because that indicated to them that Prostate Cancer can happen to any male; there were others (mostly unacculturated), who suggested the following:	Cover of the Booklet: Image	We will search for stock photos of real people; however we will not use celebrities since we are not trying to endorse screening per se.	We have included rough images and stock photos of real people, pictures of a man with his family, as well as one of a man with
 Having actual pictures of real people, like them, to identify with (more common and dressed down) 			his doctor.
To use Hispanic celebrities in entertainment or sports, particularly if they themselves have had Prostate Cancer			
Some suggested a picture of a man with his family and the doctor			
 Or, simply, Latino male patient of the proper age and make-up talking to his Latino doctor 			
Many participants (particularly unacculturated)	Design of the Booklet:	Recommendation was made to	Test colors, slide design,
felt the color of the booklet (brown color), was dull and depressing	Color / Impact	use more exciting or vibrant colors – colors mentioned most were green and blue. Page 8 of ACS PCDA Final Report Page 33 of ACS PCDA	and stock photos.
		Create new versions with different color schemes (i.e. blue/green, red/yellow).	
All participants liked the general statement	Intro of the Booklet:	No change needed.	N/A
'Prostate cancer affects many men'	Comprehension		
Most participants focused on the statement in	Intro of the Booklet:	Slide 3 is clear about benefits and	N/A
the introduction 'this test has benefits' and overlooked the remaining statement 'and risks with testing'	Comprehension	risks.	

Problem / Issue Identified	Description	Strategy	Disposition
Participants liked the bottom box of this page; however their interpretation was that the booklet was encouraging them to be tested.	Intro of the Booklet: Figures and Graphics	Not applicable to slide-set.	N/A
"The problem with PC is that it is a silent killer. You may feel fine but you may have it. That is why by testing for PC you can find out."			
"Finding out you have cancer is not a game. This is serious."			
All participants liked the graphs, charts and illustrations in the booklet. The information and data are clear, informational and impactful, and put things in perspective. "Now I understand why frequent urination is a side effect of an enlarged prostate." "I like the information presented this way. It is easy to understand. I did not know about these facts. [The header of the charts] this could make a good part of the cover to call attention	Design of the Booklet: Figures and Graphics	No change needed per previous testing. However, we did make the pictographs specific to lifetime risk of developing and dying from prostate cancer for Hispanics.	N/A
to the booklet." The information at the bottom of page 6 (in the colored box) in the booklet comes across as redundant to the audience.	Design of the Booklet: Figures and Graphics	The statement about risk increasing with age is not in the slide-set.	
Participants all agreed that the layout and the way the summarized information is presented, was well done and came across less redundant and easier to read and understand.	Design of the Booklet: Figures and Graphics PC Testing Summary	No changes needed.	N/A

Problem / Issue Identified	Description	Strategy	Disposition
The information presented on this page captures the key ideas, and avoids some of the statements that appear conflictive and for some difficult to understand. "I think the way this information is presented is good and easier to understand. Rather than on other pages they tell you the same thing and right after they tell you the opposite."	Design of the Booklet: Figures and Graphics PC Testing Summary	Pages 16-19 of slides, no changes needed.	
For some (participants that get periodic exams, higher education, and higher income levels); the purpose of this page was understood and recognized that they were given these facts to make a decision.	Design of the Booklet: Figures and Graphics PC Testing Summary	Pages 16-19 of slides, no changes needed.	N/A
For other participants (mostly participants with lower education and most of the Mexicans), took issue on the titles 'Possible benefits to you' and 'Risks to you'. Their claim is that there is NO benefit by not taking the test and the ONLY risk is not taking the test.	Design of the Booklet: Figures and Graphics PC Testing Summary	The booklet should be reevaluated to determine if it needs to be a 'Decision Aid', or not. Page 38 of ACS PCDA Final Report	Added messages throughout to place emphasis that a decision should be made by them.
They are seeking information and guidance to take a PC exam, not alternatives. "You know how it is for us (Hispanics) about this issue (PC testing) if you give us an alternative the answer is easyit will always be noyou and I know that"		The slide set remains a decision aid. Need to focus on how to convey that there are risks to having the test.	
Many participants agreed that the layout of the information and how the message was conveyed made sense to them.	Design of the Booklet: Figures and Graphics Self-Testing Summary	To be more impactful and encourage the audience, there should be a statement placed in a prominent location on a call to action to talk to their doctor about their options. Page 27-28 of ACS PCDA	This is addressed with the addition of the following slide – Slide 29.

Problem / Issue Identified	Description	Strategy	Disposition
Only a few of the participants realized that this was actually a self-administered test to make the checks and them ultimately making their own decision to act.	Design of the Booklet: Figures and Graphics Self-Testing Summary	We may move the ACS recommendation up front and make the language stronger about "you should talk to your doctor about the test and whether it is right for youthis information will help you talk to your doctor."	This is addressed in on the following slide – Slide 27.
Only a few of the participants understood the significance of the balance in the image. They felt that the balance image should be shown weighting heavier on the 'Test' side, symbolically meaning that they are seeking the information of the booklet to encourage them to be tested, not as a booklet that wants to educate them to make an informed decision on their own.	Design of the Booklet: Figures and Graphics Self-Testing Summary	No need to change.	N/A
Participants had to look for clues to find where they fit, when they are not the exact ages or races mentioned in the booklet. It seems as though the data on age is too broad and perhaps additional age range details needs to be provided. "What about if I am not 50 yet? What are my chances? And what about I am 50 to 60 years? I think they need to provide more detail."	Specific Information: Target Population: Age, Race, etc.	Consideration should be given to include a factual statement e.g. a statistic number, not percentage, of men that will be diagnosed with PC during their life or will die of PC in order to capture the attention of the audience. Many participants would welcome PC statistics and facts as they apply to Latinos. Page 40 of ACS PCDA Final Report Page 20 of ACS PCDA We should modify the pictographs to lifetime risk of developing and dying from prostate cancer for Hispanics.	We have modified the pictographs to lifetime risk of developing and dying from prostate cancer for Hispanics.

Problem / Issue Identified	Description	Strategy	Disposition
Some participants were confused as to why the only reference to Race in the booklet is for African American and that there is not equivalent or additional information for Latinos	Specific Information: Target Population: Age, Race, etc.	Evaluate ways to ensure that the reader understands how the facts apply to him personally. Page 38 of ACS PCDA Final Report Since we have modified the pictographs, the statement about Black race should be less confusing. We could not find specific data for Blacks of Hispanic ethnicity: Cuban, Puerto Rican, Dominican, etc.	Since we have modified the pictographs to reflect probabilities for Hispanic men, the statement about Black race should be less confusing. We could not find specific data for Blacks of Hispanic ethnicity: Cuban, Puerto Rican, Dominican, etc.
For participants that take PC testing today, the information presented here was very helpful. They are reluctant to ask questions and just accept their results. They assume that their doctor will tell them more if necessary.	Specific Information: Biopsies	N/A	N/A
Some participants misinterpreted the information about biopsies as an alternative to the PSA and rectal exams. "I liked the comment about biopsy – I did not know about it. I like it as an alternative. I'll ask my doctor about it next time I see him."	Specific Information: Biopsies	Although the slides seem to be clear that a biopsy is done after an abnormal PSA or DRE and because there was some confusion about it being an alternative, we should add a statement that a biopsy is not a screening test.	This is addressed with the addition of the following slide – Slide 17. This slide also includes what a biopsy is and what the risks and side-effects are.
All participants claimed that they did not believe the myth that cancer will spread if it is exposed to air during surgery. Only few had heard about this myth. A few of the Bicultural participants were not too convincing in their own answer when asked, which leads to believe that they probably did not quite understand the paragraph in the box.	Specific Information: Myths About Treatment	N/A – Myths part is not in the slides	N/A

Problem / Issue Identified	Description	Strategy	Disposition
Problem / Issue Identified The perception of a PC test, for most, is always negative, difficult and hard to overcome. While some realize the importance of PC testing (the image of the test is not a pleasant experience), it was apparent that they struggle and debate in their minds to do it or not. The main difficulty for Hispanics to overcome in considering a PC test is no doubt the rectal exam. Although lack of education is partially the reason, there is still the impact of 'el que diran' ('what will people think of me') and 'The Machismo' ('protecting my manhood') that is still prevalent for most of these people, no matter how long they have lived in the US or how acculturated they are. This aversion stems from generations of 'The Machismo' demonstration and is recognized and prevalent in their life today. One man described it as "feeling violated".	Specific Information: PC Testing Perception of Test Specific Information: PC Testing Rectal Exam	Strategy Suggestions? Fear of a rectal exam was an area that men had a lot of concerns about. It was not understood (based on the testing results) the ACS position that DRE is not needed to be screened. Notes from Conference Call with ACS Perhaps we can add a statement that PSA can be done with or without the DRE and address why it may be helpful if they do	Add a statement that PSA can be done with or without the DRE? Add a statement that DRE, though it may be embarrassing or uncomfortable, can help find cancer that the PSA may miss?
Some participants admitted how difficult it was to overcome and for others it was thinking of the need to be healthy for their family's sake. The reality is that many participants are seeking help and encouragement to do a PC		decide to get screened?	
test, not to debate the issue of doing it or not. "I don't like the way the test is done, but I have to do it for my family. I really have to encourage myself."			

Problem / Issue Identified	Description	Strategy	Disposition
Some of the men that are being tested admitted that it was not until they recognized that being a man really means taking care of themselves for the benefit of their family (that needs them for both economic and moral support). This is the motivation that finally encouraged them to take action.	Specific Information: PC Testing	Maybe add general health messages about why it is important to go to the doctor, look after your health and what is best for you and your family?	This is addressed on the following slides – Slides 22 and 29.
 The call to action for most participants to go to the doctor for a PC test, even after reading the booklet, could be due to the following: Lack of familiarity with the topic of PC testing, pertinent medical terminology, as well as low levels of education These men felt that the doctor is a trained professional and as a consumer of their services, many participants felt that they are not in a position to take control of their testing decisions The position of ACS was not clear to many participants – "so what does the ACS recommend for me?" This is not clearly stated until page 14 of the booklet and 	Message of the Booklet: Booklet Comprehension	Add a statement that this (preferences) is one area where the doctor is not the expert – you are. Suggest moving the ACS recommendation up front.	This is addressed in the following slide – Slide 24.

Problem / Issue Identified	Description	Strategy	Disposition
Also, summarized below are different call to action claims that from participants, based on personal situation, sense of urgency and importance placed on PC testing:	Message of the Booklet: Booklet Comprehension	N/A, strategies addressed elsewhere.	N/A
 Most participants' plan of action is to think about going to the doctor to have a PC test (some with no insurance inquired where they could go to have the tests where they can afford them.) 			
 Those who still had reluctance to consider PC testing, felt that the booklet was "the seed that is planted in their mind" to think about the benefits to either talk with a doctor or finally getting the courage to go to the doctor. 			
 For those who had insurance, their call of action was to talk to their doctor at their next opportunity about PC testing. 			
 For a few already taking PC exam with some frequency, felt their call of action is to ask their doctor more questions related to issues brought up in the booklet, i.e.: PSA interpretation, biopsy alternatives, etc., to ensure that they get more complete answers after their PC exam. 			

Problem / Issue Identified	Description	Strategy	Disposition
Participants stated the information in the booklet should be simple and easy to understand. "They should really try hard to keep it simple, friendly and conversational. I do not need a doctor using fancy language and scaring me. I need language like a doctor talking to me like a person, encouraging me to act upon what the booklet desires me to do. The booklet is communicating things the way an American doctor would do it: cold and factual. We need things delivered in a more tactful and in a friendly way, the way we like it. At the end of the day a doctor is perceived by Americans as a healer. We perceive a doctor as a savior – big difference."	Message of the Booklet: Simplicity of Translation	To keep the Hispanic audience interested in the topics, avoid starting sections with statements, such as: 'We do not know what causes cancer.' (Page 2 under ACS subtitle, Page 5 under cause of PC, Page 8 and Page 9). This made the participants question the credibility of the booklet and caused them to lose interest to continue reading. The majority of Spanish-speaking men in the U.S. are of average to below average in education level and communications should be simple and easy to understand — more than just a direct translation from English to Spanish. Page 33 of ACS PCDA Final Report Page 38 of ACS PCDA Final Report	In keeping with this concern, we were continually aware that the information being communicated needed to be simple and easy to understand.
There seemed to be some conflicting information (i.e. 'all prostate cancers are not the same' the word 'not' is missing in the Spanish translation)	Message of the Booklet: Translation	We have ensured that this error was not repeated in our slide-set translation – this has been addressed.	We have ensured that this error was not repeated in our slide-set translation – this has been addressed.
Consumer felt that there was an over emphasis with the word 'illness' throughout the booklet.	Message of the Booklet: Translation	In reviewing the preliminary translation of the slides, this was not applicable to our slide-set.	N/A

Problem / Issue Identified	Description	Strategy	Disposition
The overall tone of the pros and cons of taking the PC test was perceived to be very strong and direct. "Americans are direct, to the point. Latinos are not as blunt." "I do take my PC exams periodically. If I would have read the booklet before it would probably have made me more afraid to take it just by how the information if presented. Imagine how much more scary it is for someone that doesn't	Message of the Booklet: Tone of Translation	The information should be presented in a more conversational tone, when possible, in an attempt to sound less "direct". The booklet should be reviewed side-by-side with the English version to ensure that there are no miscommunications. Page 38 of ACS PCDA Final Report Page 38 of ACS PCDA Final Report	There were some messages when the two booklets were reviewed side-by-side. We will, however, use the English slide-set as a building block.
know about PC." There were other statements throughout the booklet that when translated, led to either participant confusion or conflicting information.	Message of the Booklet: Translation	Puge 56 Of ACS PCDA Fillul Report	N/A
The way that English translates into Spanish is sometimes more "dramatic" – One participant notes that the way the booklet was written in Spanish scared him. "This booklet leaves me happy but more worried. So far I am happy I am doing my PC testing, however once I read this, how it is written in Spanish and all the complications that may arise it really leaves me worried."	Message of the Booklet: Translation	Slide-set should be reviewed thoroughly to ensure that messages are translated as tactfully as linguistically possible.	Slide-set has been reviewed thoroughly to ensure that messages are translated as tactfully as linguistically possible.
The 'What if I am having prostate symptoms now?'- section of the booklet was inconclusive in informing them of prostate problems or if they have Prostate Cancer	Message of the Booklet: Translation	In reviewing the preliminary translation of the slides, we need to ensure we do not create the same uncertainty with regards to this section.	We ensured this was not the case with the slide-set. This is addressed in the following slide – Slide 5.
The tone of the pros and cons of taking the PC test is perceived to be very strong and direct	Message of the Booklet: Translation		

Problem / Issue Identified	Description	Strategy	Disposition
Participants that had a higher level of education, recommended and pointed out ways that the Spanish text needed to be simplified for ease of understanding such as: • 'Right now', 'a gloved lubricated finger', 'outpatient' – were not clear or properly translated • The header on the first page translated slightly differently than the English version ○ English version reads: 'Prostate cancer affects many men. There are tests to find it early.' ○ Spanish version reads: 'Prostate cancer affects many men. There are tests to discover the illness at an early stage; these tests have benefits and associated risks.' • And, in the second paragraph ○ English version reads: 'This booklet will let you decide if you want' ○ Spanish version reads: 'This booklet will help you decide if it is convenient for you"	Message of the Booklet: Translation	The information needs to be more than just a direct translation from English to Spanish. This is already being addressed in our version of the slide-set.	This was addressed in and throughout the slide-set.
"The translation is okay. Although some paragraphs are somehow disconnected and some words are not easy to understand. You can tell it came from an English document. But there is something lacking, it doesn't consider the Latino mentality of the reader. Mind you if I checked this translation in Google it is going to come out as a perfect Spanish document."		Page 8 of ACS PCDA Final Report	

Problem / Issue Identified	Description	Strategy	Disposition
Confusion in interpretation, conflicting information and discouragement. Many participants were confused by statements such as 'The research is not clear' and 'Testing is not perfect' as well as 'Can testing tell me for certain that I have Prostate Cancer' and 'Can testing tell me for certain that I do not have Prostate Cancer'. Immediately after the information about the importance of getting tested, the booklet puts the tests into question (pages 8 & 9). This made the participants lose interest in the booklet because they could not understand the message. Based on the participants, this confusion came across as conflicting and discouraging - causing them to lose interest.	Message of the Booklet: Comprehension	The table of the pros and cons was where there was the greatest amount of comprehension. Consideration should be given on placing this information closer to the front of the booklet because of the following: To provide greater emphasis on this information To set the stage for the remaining content of the booklet To be read before the reader loses interest	N/A
Although the purpose of the booklet was to provide pros and cons of PC testing, that is not how the information communicated to them. "Why would I put myself through the test if it is not clear? And if testing is not perfect, I want to see the error rate".		Page 41 of ACS PCDA Final Report	
Few participants (mostly Bicultural) knew what PSA was, partly because these were the ones that typically and routinely have their prostate checked, have heard their doctor talk about PSA or have read about it.	Message of the Booklet: Translation / Understanding Medical Terms: PC Testing / PSA	No action regarding the slide-set required.	N/A

Problem / Issue Identified	Description	Strategy	Disposition
Some of the participants that do have their	Message of the Booklet:	No action regarding the slide-set	N/A
prostate checked, claim that their doctor tells them if everything is fine or not. The doctor does not go into details and most do not read the details of the test results given to them.	Translation / Understanding Medical Terms: PC Testing / PSA	required.	
The remaining participants recognized that PSA	Message of the Booklet:	PSA vs. APE	This has been addressed
is a blood test from reading the definition; however they did not fully understand the meaning of PSA. Participants seemed interested in learning what PSA means exactly. Given from their comments, this should be given in a way that is easier to understand.	Translation / Understanding Medical Terms: PC Testing / PSA	To avoid confusion the term PSA should always be used since they live in the US and that is the medical term that will be used by the doctor. Page 35 of ACS PCDA This has been addressed and	by defining APE and then using PSA throughout.
		recommendation has been incorporated into our slide-set.	

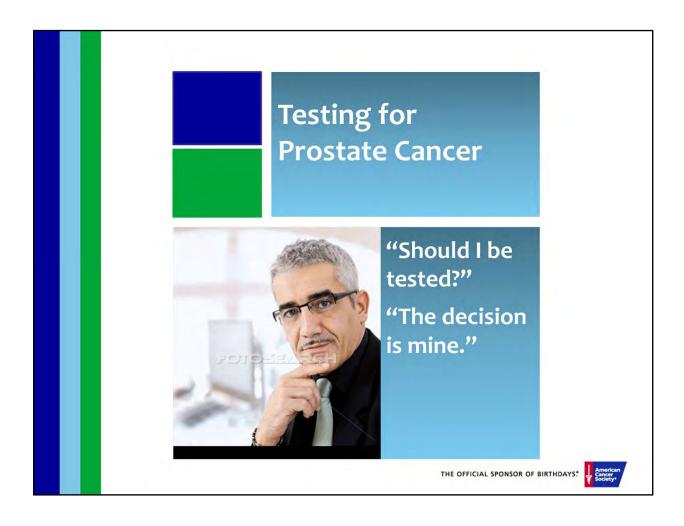
Summary Comments		

ACS Decision Aid: English Booklet, Spanish Booklet & Original English Slide-Set Comparision

ENGLISH BOOKLET	SPANISH BOOKLET	ENGLISH SLIDE-SET
Page 3 ACS recommendation	Page 2 Spanish booklet has more information than the English version – one of the bullet points is a little conflicting.	Has most of the information mentioned throughout.
Page 5 Risk Factors: Age, Family History, Race	Page 5 Risk Factors: Age, Family History, Race	On "The decision is yours "slide some of the same statements are made, but not presented as risk factors. Age: "The chance of having prostate cancer goes up quickly after age 50." Is missing from the slide-set.
Page4 How common is prostate cancer? Prostate cancer is the most common cancer in men. The chance of having prostate cancer goes up with age.	Page 4 How common is prostate cancer? Prostate cancer is the most common cancer in men. The chance of having prostate cancer goes up with age.	Not in slide-set.
Page 9 The rectal exam is not as good as the PSA test for finding prostate cancer, but it might find cancers in some men with low PSA levels.	Page 9 The rectal exam is not as good as the PSA test for finding prostate cancer, but it might find cancers in some men with low PSA levels.	Not in slide-set.
Page 10 What is my chance of having prostate cancer based on my PSA level?	Not in the Spanish booklet.	In the slide-set.
Not in the English booklet. Similar statement Page 2 of English booklet – Page 5 of Spanish booklet	Pages 10 You can have prostate cancer and not have any symptoms. However, if you have symptoms, immediately speak with your doctor.	Not in slide-set.

ENGLISH BOOKLET	SPANISH BOOKLET	ENGLISH SLIDE-SET
Page 11 The biopsy is done as an outpatient and takes only a few minutes.	Pages 10 & 11 The biopsy is done as an outpatient and takes only a few minutes.	Takes about an hour. Is what is on the slide-set
Page 11 Not in the English booklet.	Page 11 The biopsy is done as an outpatient and takes only a few minutes. If the biopsy shows that there are cancer cells, you and your doctor will decide how to treat the cancer, or if treatment is needed at the moment.	Not in slide-set.
Page 14 Know the facts about: Ask questions and talk to others:	Page 14 Know the facts about: Ask questions and talk to others:	Not in slide-set.
Last Page Near the end of the booklet ACS recommendations stated once again.	Page 14 ACS recommendations stated once again.	Starting at age 50, talk to your doctor about the pros and cons of testing. Then decide if testing is the right choice for you. This statement is missing from slideset.
 End of Booklet Some reasons to be tested: English version: I will have peace of mind when I know the test results. I will know if I have prostate cancer or not. I will have a better chance of getting cancer treatment if a cancer is found early 	 End of Booklet Some reasons to be tested: Spanish version has an extra bullet point as well as rewording on another. I will have peace of mind when I know the test results. My family and I will know if I have prostate cancer or not. I will have a better chance of getting cancer treatment that could save my life if a cancer is found early. I have some of the risk factors that increase my risk of having prostate cancer. 	The slide-set has the English wording.

ENGLISH BOOKLET	SPANISH BOOKLET	ENGLISH SLIDE-SET
 End of Booklet Some reasons not to be tested: English version: I will worry about the test results. I might find a prostate cancer that never would have caused me problems or shortened my life. I will have to deal with treatment and its side effects. 	 End of Booklet Some reasons not to be tested: Spanish version has an extra bullet point as well as rewording on another. I will worry about the test results. I might find a prostate cancer that never would have caused me problems or shortened my life. I will have to deal with treatment and its side effects. I could have a biopsy when I did not need one. 	 The slide-set has most of the English wording. I might find a prostate cancer that never would have caused me problems or shortened my life. If cancer is found I might have to deal with treatment and side effects.
Not in the English booklet.	Page 15 Myth about cancer spreading when exposed to air during surgery.	Not in slide-set.
Not in the English booklet.	Last Page of Booklet Has a summary box of the booklet that most ACS participants (based on ACS findings) liked.	Not in slide-set.



Title of the slide modified:

The second "thought" is now a statement – not a question.

Original: "Is it the right choice for me?"

New: "The decision is mine."

In response to ACS findings that slight modifications and editing may be needed to ensure that the call to action is clear.

The title was modified and the question "Is it the right choice for me?" is now a statement "The decision is mine."

This not only clarified that there is a decision for them to make, it also allowed for ease of translation for the Spanish version.

- Throughout the slides, changes were made to the color and images, in response to ACS test results of the Spanish version of the booklet and feedback from Hispanic men. They wanted more vibrant colors, images/photos of real men, and some images of family.
- Please note that the images/photos used and slide designs are placeholders and will be tested with Hispanic men.



Prostate cancer affects many men.
There are tests to find it early.



This information will help you decide if you want to be tested for prostate cancer.

2

Is testing the right choice for me?

- There may be both benefits and risks with prostate cancer testing and treatment.
- Research has not yet proven that the benefits outweigh the risks.

Testing, also called screening, means checking for possible cancer when you have **no** symptoms.

3

Added the following:

New: Testing, also called screening, means checking for possible cancer when you have **no** symptoms.

Is testing the right choice for me?

- Here we will talk more about prostate cancer and the possible benefits and risks of testing and treatment.
- After viewing this slide show we hope you will be able to decide if you would like to be tested.
- If you have additional questions after viewing this slide show, please talk to your doctor or medical counselor.

1

The following change was made to the third bullet:

Original: • If you have additional questions please talk to your doctor or ask the medical counselor on site.

New: • If you have additional questions after viewing this slide show, please talk to your doctor or medical counselor.

The bullet point was also modified after medical expert review.

The slide was modified for consistency and clarity, as well as for ease of translation for the Spanish version.

What if I am having prostate symptoms?

The information in this slide show is to help men who do not have any prostate symptoms decide if they want to be tested.

You should talk to your doctor right away if you have:

- · trouble passing urine,
- blood in your urine, or
- pain when you pass urine

These are often symptoms of other prostate problems, but they can also be caused by prostate cancer. The only way to know what is wrong is to see a doctor.

5

Title of the slide modified:

Original: "What if you are having prostate symptoms?" **New:** "What if I am having prostate symptoms?"

The slide was modified for consistency and clarity, as well as for ease of translation for the Spanish version.

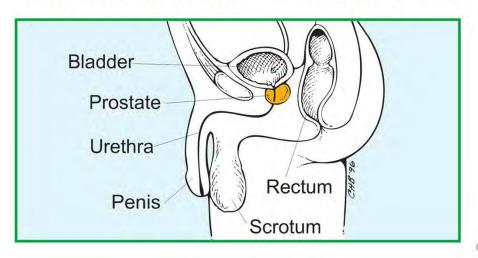
Please note that we ensured to stay true to the meaning of the English version:

"What if I am having prostate symptoms now?" NOT

"What if I am having prostate cancer symptoms now?" as translated in the Spanish booklet. (Page 5)

What is prostate cancer?

- Cancer begins in your body when normal cells start to grow out of control.
- In prostate cancer, prostate cells grow out of control.
- Cancer cells can spread and affect nearby organs. They can also spread to distant parts of the body and cause problems.



Title of the slide modified:

Original Title: "About prostate cancer"

Original Subtitle: "What is prostate cancer?"

New Title (without subtitle): "What is prostate cancer?"

The slide was modified for consistency as well as for ease of translation for the Spanish version.

Are all prostate cancers the same?

Prostate cancer can cause death. But not all prostate cancers are the same.

- Many prostate cancers grow slowly. These cancers, if left untreated, may not produce noticeable problems for many years.
- Some prostate cancers are aggressive and grow quickly. They can spread to other parts of the body where they cause severe pain and other problems, and can even cause death.

Ď,

Title of the slide modified:

Original Title: "About prostate cancer"

Original Subtitle: "Are all prostate cancers the same?"

New Title (without subtitle): "Are all prostate cancers the same?"

The slide was modified for consistency as well as for ease of translation for the Spanish version.

Both bullet points were modified after medical expert review and per the recommendation of a physician collaborator for the protocol.

The following changes were made:

First Bullet

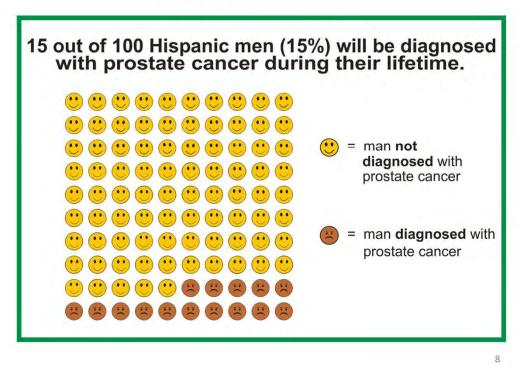
Original Text: • Many prostate cancers grow slowly. These do not usually cause any harm. **New** Text: • Many prostate cancers grow slowly. These cancers, if left untreated, may not produce noticeable problems for many years.

Second Bullet

Original Text: • Some prostate cancers grow fast.

New Text: • Some prostate cancers are aggressive and grow quickly.





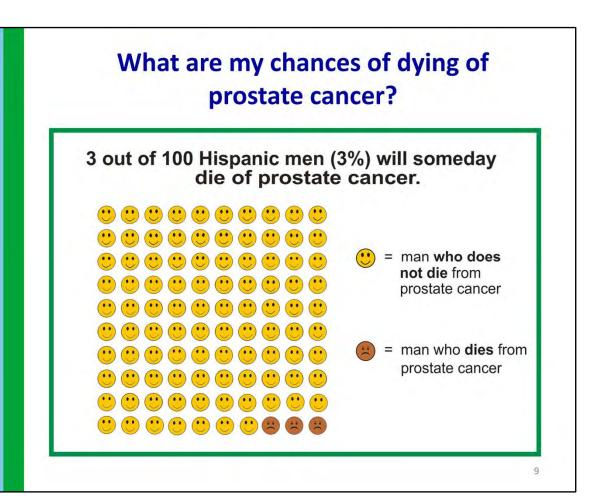
The changes below were made to make the slide to make the content relevant to the target population, and also in response to ACS findings that Hispanic men were confused as to why the only reference to race was for African Americans. They wanted to know information for Latinos. Also, the data on age confused some people "What if I am 60 years old?". Information obtained from SEER data:

Original: 17 out of 100 men (17%) age 50 will be diagnosed with prostate cancer during their life.

New: 15 out of 100 Hispanic men **(15%)** will be diagnosed with prostate cancer during their lifetime.

Changed from risk at age 50 to lifetime risk.

Changed from all men to Hispanic men.



The following changes were made to make the slide more relevant to the target population. Although we are using data for Hispanic men, the number represented in the icon array did not change.

<u>Information obtained from SEER data:</u>

Original: 3 out of 100 men (3%) age 50 will some day die of prostate cancer.

New: 3 out of 100 Hispanic men (3%) will someday die of prostate cancer.

Changed from risk at age 50 to lifetime risk.

Changed from all men to Hispanic men.

What are the tests to find prostate cancer early?

A **PSA blood test** and a **DRE** can tell your doctor about your prostate.

- PSA stands for Prostate Specific Antigen.
- DRE stands for Digital Rectal Exam.

10

Title of the slide was modified:

Original Title: "Prostate Cancer Testing"

Original Subtitle: "PSA stands for Prostate Specific Antigen."

New Title (without subtitle): "What are the tests to find prostate cancer early?"

The subtitle and the information that followed on the original slide will be on the slide that follows.

The slide was modified for consistency, content flow, and for ease of translation for the Spanish version.

The original slide was essentially divided to define up front what tests are available for early detection and to add what DRE stands for.

What is a PSA test?

- PSA is a protein made by the prostate gland.
- The PSA test measures how much of this protein is in your blood.
- It is done by having a small amount of blood taken from a vein in your arm.

11

Continuation of slide 10.

Title of the slide was modified:

Original Title: "Prostate Cancer Testing"

Original Subtitle: "PSA stands for Prostate Specific Antigen."

New Title (without subtitle): "What is a PSA test?"

What is a Rectal Exam?

- The doctor puts a gloved, lubricated finger into your rectum to feel your prostate gland.
- A rectal exam can tell if the prostate size, shape, and texture are normal.
- If you decide to be screened for prostate cancer, you can choose to have the PSA or the PSA and the DRE
- Some people may find the DRE embarrassing or uncomfortable. However, the DRE may help to detect abnormalities or cancer that the PSA may miss.

12

Title of the slide was modified:

Original Title: "Prostate Cancer Testing"

Original Subtitle: "Rectal Exam"

New Title (without subtitle): "What is a Rectal Exam"

The slide was modified for consistency, content flow, and for ease of translation for the Spanish version.

Also added the following bullet points:

The second bullet point was further modified after medical expert review.

New: • If you decide to be screened for prostate cancer, you can choose to have the PSA or the PSA and the DRE.

New: • Some people find the DRE embarrassing or uncomfortable. However, the DRE may help to detect abnormalities or cancer that the PSA may miss.

This was in response to literature review and ACS finding that the Latino men feared the rectal exam, as well as to clarify that screening for prostate cancer can be done with the PSA <u>or</u> the PSA <u>and</u> the DRE.

Can testing tell me for certain that I do not have prostate cancer?



No. There is no perfect test that can detect prostate cancer.

13

The following statement was modified:

Original: There is no perfect test to look for prostate cancer.

New: There is no perfect test that can detect prostate cancer.

Can testing tell me for certain that I do not have prostate cancer?

The rectal exam is not perfect.

- If your rectal exam does not suggest cancer, you can still have prostate cancer.
- Most cancers cannot be felt by rectal exam.
- But sometimes rectal exams can find cancer even when the PSA level does not suggest cancer.

14

Title of the slide was modified:

Original Title: "The tests for prostate cancer are not perfect"

Original Subtitle: "Rectal Exam"

New Title: "Can testing tell me for certain that I do not have prostate cancer?"

New Subtitle: "The rectal exam is not perfect."

Can testing tell me for certain that I do not have prostate cancer?

The PSA test is not perfect.

There is no PSA level that says for sure that prostate cancer is present or is not present.

- PSA levels can be low when cancer is present.
- Your chance of having prostate cancer goes up as your PSA level goes up.
- PSA can be high in prostate cancer, and also with prostate infections and other prostate problems.
 So, having a high PSA does NOT always mean that you have prostate cancer.

If your PSA level is high, you will need other tests to find out why.

Title of the slide was modified:

Original Title: "The tests for prostate cancer are not perfect"

Original Subtitle: "PSA Test"

New Title: "Can testing tell me for certain that I do not have prostate cancer?"

New Subtitle: "The PSA Test is not perfect."

How do I find out if I have prostate cancer?



If your PSA level or your rectal exam suggests cancer, you may need a **biopsy** of your prostate gland.

A biopsy is <u>not</u> a test used for screening.

16

Removed:

Biopsy description – this will be elaborated on the following slide.

What is a biopsy and what are the risks?

A biopsy is a test to diagnose prostate cancer.

- An ultrasound probe is inserted into the rectum.
- The probe is used to guide a needle.
- Many tiny pieces of the prostate gland are removed.
- These tiny pieces are looked at under a microscope to look for cancer cells.
- It is done as an outpatient and takes about an hour.
- There is a low risk of bleeding and infection.

There are some risks and side-effects that can occur with a biopsy.

- · Low risk of bleeding from rectum.
- Low risk of infection.
- Blood in urine is common and resolves with treatment.

17

Added the following:

Title: "What is a biopsy and what are the risks?"

"A biopsy is a test to diagnose prostate cancer."

- An ultrasound probe is inserted into the rectum.
- The probe is used to guide a needle."
- There is a low risk of bleeding an infection."

Removed/changed the following:

- •A biopsy is done with a needle.
- •The biopsy is done as an outpatient and takes only about an hour.

Change was in part to the response to ACS findings – some participants believed that biopsy could be used as a screening test, the goal is to clarify that it is not.

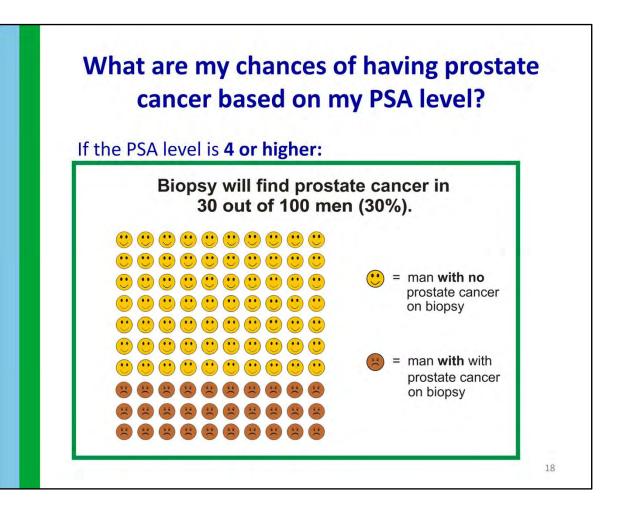
The risks and side-effects of that can occur with a biopsy, were added after medical expert review and per the recommendation of a physician collaborator for the protocol.

The following bullet points were added:

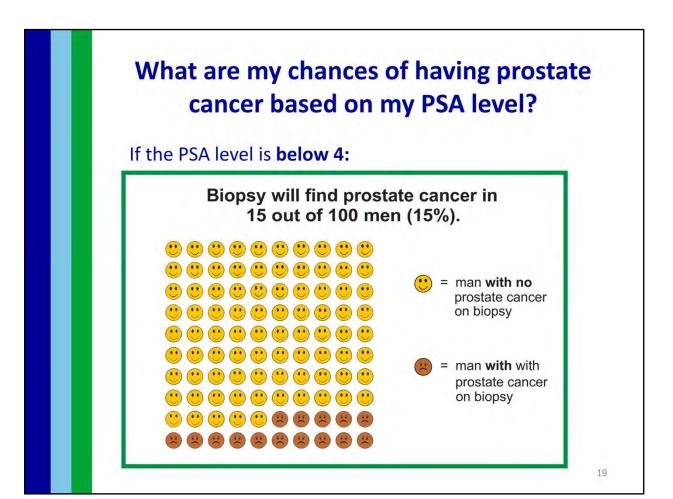
There are some risks and side-effects that can occur with a biopsy.

- Low risk of bleeding from rectum.
- Low risk of infection.
- Blood in urine is common and resolves with treatment.

[&]quot;A biopsy is not a test used for screening."



This icon array, although in the original English slide-set, it was not included in the Spanish ACS materials tested. The information was taken from the English booklet and original English slide-set. It was translated to Spanish by the mechanism described in the flowchart and will be tested.



This icon array, although in the original English slide-set, it was not included in the Spanish materials tested. The information was taken from the English booklet and slide-set and translated to Spanish by the mechanism described in the flowchart.

What happens if I <u>do</u> get tested for prostate cancer?

You get a PSA test and maybe a rectal exam.

If your test results are cause for concern, you have a biopsy.

Possible benefits if I do get tested:

- Testing may detect an early prostate cancer while it is small and before it has spread.
- If it is detected early, there is a better chance of being treated and cured.
- You may avoid pain and suffering from cancer.
- · Getting tested may give you peace of mind.

20

Title of the slide modified:

Original Title: "What happens if you do get tested for prostate cancer?"

Original Subtitle: "Possible benefits if you get tested"

New Title: "What happens if I do get tested for prostate cancer?"

New Subtitle: "Possible benefits if I do get tested:"

In the first bullet point, "find" was replaced by "detect".
In the second bullet point, "found" was replaced by "detected".

What happens if I <u>do</u> get tested for prostate cancer?

Possible risks if I do get tested:

- Your PSA level may be low, even though cancer is there.
- You may worry about the results.
- Testing may detect a cancer that might never have caused you any problems.
- Testing may lead to side effects from treatment.
 These include problems controlling your urine, problems with your bowels, and/or problems having sex.

21

<u>Title of the slide modified:</u>

Original Title: "What happens if you do get tested for prostate cancer?"

Original Subtitle: "Possible risks if you get tested"

New Title: "What happens if I do get tested for prostate cancer?"

New Subtitle: "Possible risks if I do get tested:"

In the third bullet point, "find" was replaced by "detect".

What happens if I do <u>not</u> get tested for prostate cancer?

You have regular check-ups but no prostate cancer testing. You can change your mind and be tested in the future.

Possible benefits if I do not get tested:

- You avoid the worry that you might have from testing.
- You avoid being treated for a cancer that might have never caused you any problems.
- You avoid the side effects that can occur with treatment.

22

<u>Title of the slide modified:</u>

Original Title: "What happens if you do not get tested for prostate cancer?"

Original Subtitle: "Possible benefits if you do not get tested"

New Title: "What happens if I do <u>not</u> get tested for prostate cancer?"

New Subtitle: "Possible risks if I do not get tested:"

The slide was modified for consistency as well as for ease of translation for the Spanish version.

Changed:

Original:....might have never cause you.....

New:might have never caused you....

What happens if I do <u>not</u> get tested for prostate cancer?

Possible risks if I do not get tested:

- You may have an early prostate cancer, and you won't know this.
- You may have a prostate cancer that will later cause symptoms or shorten your life, and not have the chance to find it early.

23

Title of the slide modified:

Original Title: "What happens if you do not get tested for prostate cancer?"

Original Subtitle: "Possible risks if you do not get tested"

New Title: "What happens if I do not get tested for prostate cancer?"

New Subtitle: "Possible risks if I do not get tested:"

٧

How do I decide if testing is the right choice for me?

Weigh your options and decide what is important to you.

- There are many reasons men decide to be tested or to not be tested for prostate cancer.
- Some reasons are listed on the next slide.
- Think about which of these reasons are important to you.

 Talk about testing with your family and those who care about you.

The decision is yours.

This is one area where the doctor is not the only expert. Once you know the facts, you can decide if testing is important for you.

24

Title of the slide modified:

Original Title: "How do you decide if testing is the right choice for you?" **New** Title: "How do I decide if testing is the right choice for **me**?"

Added the following bullet point:

New: • Talk about testing with your family and those who care about you.

Added the following statement:

New: This is one area where the doctor is not the only expert. Once you know the facts, you can decide if testing is important for you.

The slide was modified for consistency as well as for ease of translation for the Spanish version.

Literature review showed that family opinion and support is important for Hispanic men. The bullet point being added is in the English and Spanish booklet, however was not included in the original slide-set. The last statement was added in part to ACS finding that patients felt that the doctor is a trained professional and that they (as patients) are not in a position to take control of their testing decisions, and phrasing was modified after medical expert review.

Which is more important to you... A or B?

A. Some reasons a man may choose to be tested:	B. Some reasons a man may choose <u>not</u> to be tested:
I will have peace of mind when I know the test results.	I will worry about the test results.
I will know if I have prostate cancer or not.	I might find a prostate cancer that never would have caused problems or shortened my life.
I will have a better chance of getting cancer treatment if a cancer is detected early.	If cancer is detected I might have to deal with treatment and side effects.

25

Title of the slide modified:

Original Title: "So What's Important to You?"

New Title: "Which is more important to you...A or B?"

The last "reason" was slightly modified and "found" was replaced by "detected".



You may wish to be tested if:

- · You value finding cancer early
- You are willing to be treated without definite benefit
- You are willing to risk urinary, sexual, or bowel injury from treating early prostate cancer (with treatment such as surgery and radiation)

You may wish to not to be tested if:

- You place a higher value on avoiding the risks of screening and treatment, such as worry or problems with urinary, sexual, or bowel function
- You are willing to accept the chance that you may have an aggressive form of prostate cancer and not know about it before it causes you harm

The decision is yours.

26

Title and order of the slide were modified:

Original Title: "To Help Men Decide"

New Title: "How do I decide?"

The subtitle was slightly modified:

Original Subtitle: You may wish to be tested if:

New: You may wish to be tested if:

Original Subtitle: You may not wish to be tested if:

New: You may wish to not be tested if:

Added the following:

New: (with treatment such as surgery and radiation)

The following bullet point was also modified after medical expert review:

Original: • You are will willing to accept the chance that you may have prostate cancer and not know about it before it causes you harm.

New: • You are willing to accept the chance that you may have an aggressive form of prostate cancer and not know about it before it causes you harm.

What does the American Cancer Society recommend?

The American Cancer Society says that all men should make an informed decision about testing.

Starting at age 50, talk to a doctor or medical counselor about prostate cancer testing and treatment.

- You should think through the risks and possible benefits;
- Think about what is important to you;
- Then you should decide if testing is the right choice for you.

27

Title and order of the slide were modified:

Original Title: "The American Cancer Society says that all men should make an informed decision about testing"

New Title: "What does the American Cancer Society recommend?" **New Subtitle:** "The American Cancer Society says that all men should make an informed

decision about testing."

Added the following:

New: Starting at age 50, talk to a doctor......

What does the American Cancer Society recommend?

- If you are African American or have a father or brother who had prostate cancer before age 65, have this talk with your doctor starting at age 45.
- Men with 2 or more close relatives who had prostate cancer at an early age should have this talk starting at age 40.
- If you decide to be tested, you should have the PSA blood test with or without a rectal exam. How often you are tested will depend on your PSA level.

28

Title and order of the slide were modified:

Original Title: "The decision is yours "

New Title: "What does the American Cancer Society recommend?"

What should I do next?

- Talk to your doctor about the screening tests.
- Think about what is important to you.
- Decide what is best for you and your family.



29

This is a new slide:

Most if the information included in this slide is new. This is from ACS feedback that the call to action was unclear (patients thought it was mean to encourage men to get screened vs. encouraging men to discuss screening with the doctor). Literature review showed that family is was what Hispanic men said motivated some of them to go to the doctor. This slide is meant to summarize important points of the slide-set.

Where can I get more information to help me decide?

- American Cancer Society
 - 1-800-227-2345
 - www.cancer.org/prostatemd
- U.S. Centers for Disease Control and Prevention
- Mayo Clinic
- Foundation For Informed Medical Decision Making

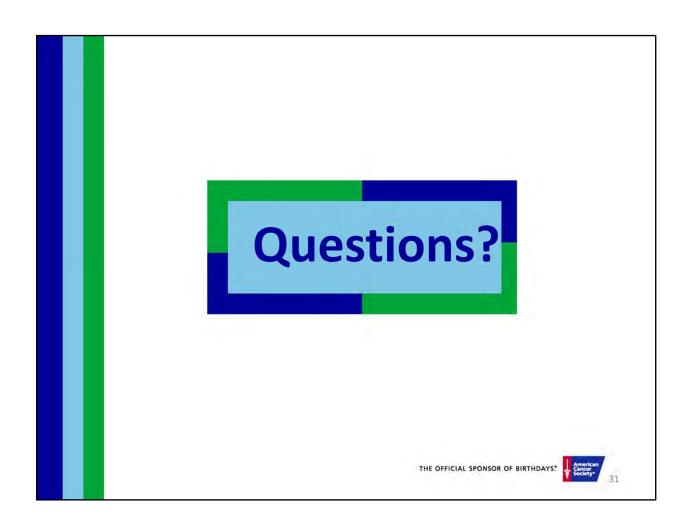
For cancer information, answers, and support, call your American Cancer Society 24 hours a day, 7 days a week at 1-800-227-2345.

30

Title and order of the slide were modified:

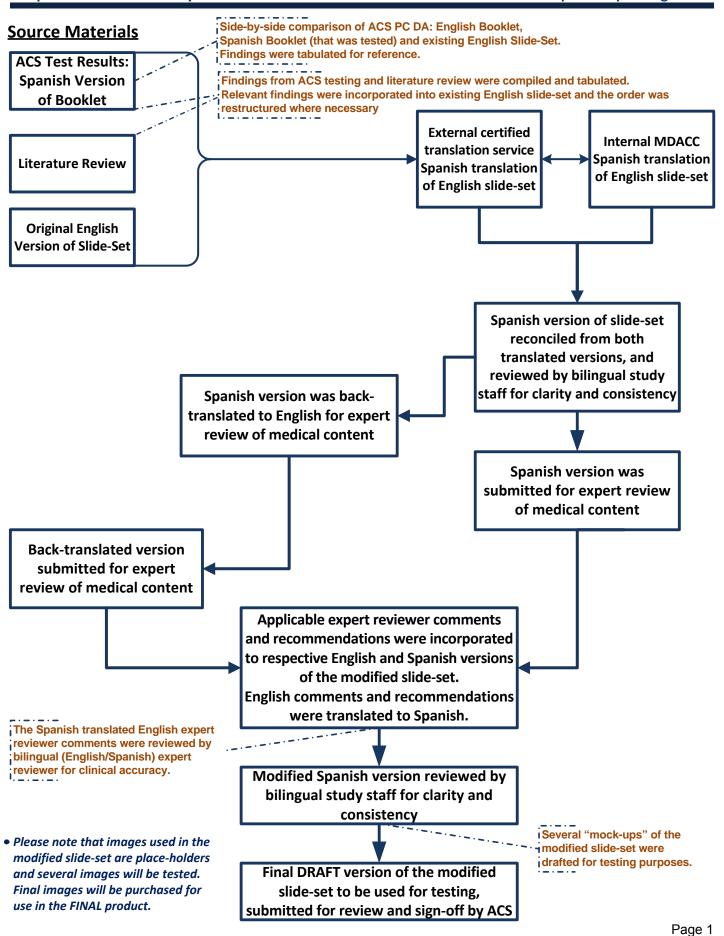
Original Title: "More information is available to help you make a decision"

New Title: "Where can I get more information to help **me** decide?



Conceptual Flowchart for Translation and Modification of Slide-Set Protocol 2011-0747

Adaptation of the ACS Early Detection of Prostate Cancer Patient Decision Aid for Spanish Speaking Men



Pruebas de detección del cáncer de próstata



"¿Debería hacerme las pruebas?"

"La decisión es mía."





El cáncer de próstata afecta a muchos hombres.

Existen pruebas para detectarlo temprano.



Esta información le ayudará a decidir si usted quiere hacerse las pruebas de detección de cáncer de próstata.

¿Son las pruebas de detección la mejor opción para mí?

- Puede haber tanto beneficios como riesgos con las pruebas de detección y el tratamiento para cáncer de próstata.
- Las investigaciones aún no han demostrado que los beneficios son mayores que los riesgos.

"Detección" significa buscar cáncer **antes** de tener síntomas.

¿Son las pruebas de detección la mejor opción para mí?

- Aquí hablaremos más sobre el cáncer de próstata y los posibles beneficios y riesgos de las pruebas de detección y el tratamiento.
- Después de ver esta presentación, esperamos que usted pueda decidir si quiere hacerse o no las pruebas de detección.
- Si tiene otras preguntas después de ver esta presentación, por favor hable con su médico o consejero médico.

¿Qué debo hacer si tengo síntomas de la próstata?

La información de esta presentación es para ayudar a hombres que no tienen síntomas de la próstata a decidir si quieren hacerse las pruebas de detección.

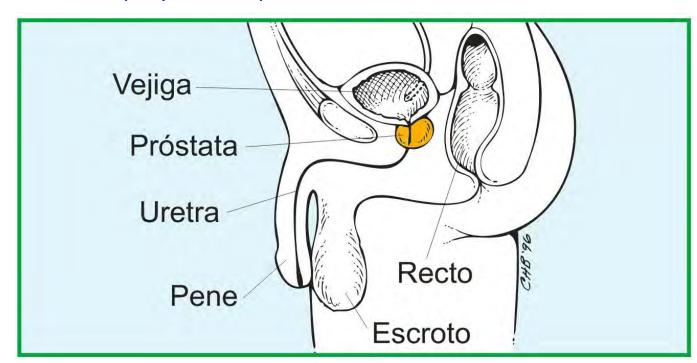
Hable con un médico inmediatamente si tiene:

- problemas al orinar,
- sangre en la orina, o
- dolor al orinar

Estos síntomas a menudo son causa de otros problemas de la próstata, pero también pueden ser causados por el cáncer de próstata. La única manera de saber lo que está mal es consultar un médico.

¿Qué es el cáncer de próstata?

- El cáncer comienza en su cuerpo cuando células normales empiezan a crecer sin control.
- En el cáncer de próstata, las células de la próstata crecen sin control.
- Las células de cáncer se pueden propagar y afectar órganos cercanos. También se pueden propagar a partes distantes del cuerpo y causar problemas.



¿Son iguales todos los casos de cáncer de próstata?

El cáncer de próstata puede causar la muerte, pero no todos los casos de cáncer de próstata son iguales.

- Muchos casos de cáncer de próstata crecen lentamente.
 Por lo general, si no son tratados, estos cánceres pueden no causar problemas por muchos años.
- Algunos casos de cáncer de próstata son más agresivos y crecen rápidamente. Éstos pueden propagarse a otras partes del cuerpo, donde pueden causar dolor intenso y otros problemas, e incluso pueden causar la muerte.

¿Cuál es mi probabilidad de desarrollar cáncer de próstata?

15 de cada 100 (15%) hombres hispanos serán diagnosticados con cáncer de próstata en su vida.

- = hombre no diagnosticado con cáncer de próstata
- = hombre diagnosticado con cáncer de próstata

¿Cuál es mi probabilidad de morir de cáncer de próstata?

3 de cada 100 (3%) hombres hispanos morirán debido al de cáncer de próstata.

- = hombre que **no muere** de cáncer
 de próstata
- = hombre que **muere** de cáncer de próstata

¿Cuáles son las pruebas para detectar el cáncer de próstata en etapa temprana?

Un examen de sangre **PSA** y un **examen rectal** pueden indicarle a su médico el estado de su próstata.

- El examen PSA (por sus siglas en inglés) también se conoce como APE. APE significa Antígeno Prostático Específico en español.
- El examen rectal, DRE (por sus siglas en inglés) también se conoce como el examen rectal digital o examen rectal.

¿Qué es la prueba PSA?

- El antígeno prostático específico es una proteína producida la glándula prostática.
- La prueba PSA mide la cantidad de esta proteína que se encuentra en su sangre.
- Se hace tomando una pequeña cantidad de sangre de una vena de su brazo.

¿Qué es el examen rectal?

- El médico coloca un dedo, cubierto con un guante lubricado, en su recto para palpar la glándula prostática.
- Un examen rectal puede indicar si el tamaño, la forma y la textura de la próstata son normales.
- Si decide hacerse las pruebas de detección del cáncer de próstata, puede elegir hacerse solo la prueba del PSA o también el examen rectal.
- Para algunas personas, el examen rectal es penoso o desagradable. Sin embargo, puede ayudar a detectar anormalidades o cáncer que la prueba PSA no detectaría.

¿Pueden las pruebas de detección decirme con seguridad que no tengo cáncer de próstata?



No. No existe una prueba perfecta para detectar el cáncer de próstata.

¿Pueden las pruebas de detección decirme con seguridad que no tengo cáncer de próstata?

El examen rectal no es perfecto.

- Si su examen rectal no sugiere cáncer, aún así usted puede tener cáncer de próstata.
- La mayoría de los cánceres no pueden detectarse con un examen rectal.
- Pero algunas veces los exámenes rectales pueden detectar el cáncer aún cuando los niveles de PSA no sugieran cáncer.

¿Pueden las pruebas de detección decirme con seguridad que no tengo cáncer de próstata?

La prueba PSA no es perfecta.

No existe un nivel de PSA que diga con seguridad que el cáncer de próstata está o no presente.

- Los niveles de PSA pueden ser bajos cuando el cáncer está presente.
- Sus probabilidades de tener cáncer de próstata aumentan a medida que su nivel de PSA aumenta.
- Los niveles de PSA pueden estar altos cuando hay cáncer de próstata y también cuando hay infecciones de la próstata y otros problemas de la próstata. Por lo que, tener un nivel alto de PSA NO siempre significa que usted tiene cáncer de próstata.

Si su nivel de PSA es alto, usted necesitará hacerse otras pruebas para saber la causa.

¿Cómo saber si tengo cáncer de próstata?



Si su nivel de PSA o su examen rectal sugieren la presencia de cáncer, es posible que usted puede necesitar una **biopsia** de su glándula prostática.

Una biopsia no es una prueba de detección.

¿Qué es una biopsia y cuáles son los riesgos?

Una biopsia es un examen para diagnosticar cáncer de la próstata.

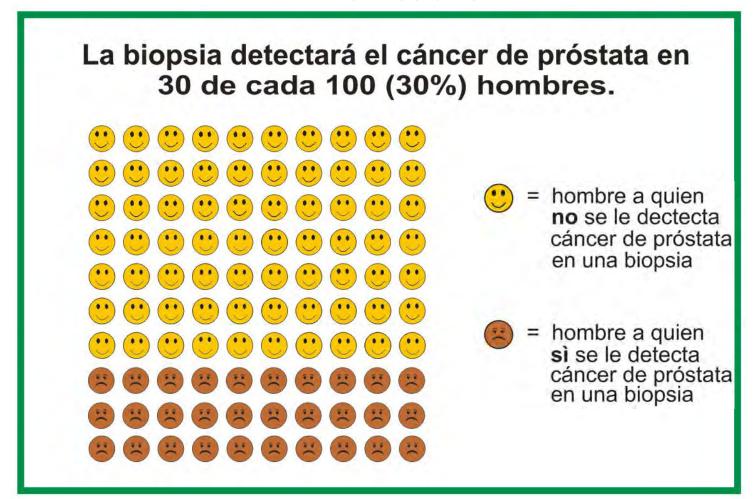
- El médico introduce una sonda ultrasónica en el recto.
- El médico utiliza la sonda para guiar una aguja.
- El médico extrae varias muestras de la glándula prostática.
- Estas muestras se observan en el microscopio para detectar células cancerosas.
- La biopsia se hace en una consulta y solamente toma alrededor de una hora.

Hay algunos riesgos y efectos secundarios que pueden ocurrir con una biopsia.

- Poco riesgo de sangramiento del recto.
- Poco riesgo de infección.
- Sangre en la orina es común y se resuelva con tratamiento.

¿Basado en mi nivel de PSA, cuál es mi probabilidad de tener cáncer de próstata?

Si el nivel de PSA es de 4 o más alto:



¿Basado en mi nivel de PSA, cuál es mi probabilidad de tener cáncer de próstata?

Si el nivel de PSA es menor de 4:

La biopsia detectará el cáncer de próstata en 15 de cada 100 (15%) hombres.



 no se le dectecta cáncer de próstata en una biopsia

= hombre a quien
 sì se le detecta
 cáncer de próstata
 en una biopsia

¿Qué pasa si me hago las pruebas de detección de cáncer de próstata?

A usted le hacen una prueba PSA y tal vez un examen rectal.

Si los resultados de sus pruebas son preocupantes, a usted se le hace una biopsia.

Posibles beneficios si se hace las pruebas:

- Las pruebas de detección pueden detectar cáncer de próstata en una etapa temprana – mientras es pequeño y antes de que se propague.
- Si se detecta en una etapa temprana, hay una mejor probabilidad de ser tratado y curado.
- Puede prevenir el dolor y el sufrimiento causados por el cáncer.
- El hacerse las pruebas le puede dar tranquilidad.

¿Qué pasa si me hago las pruebas de detección de cáncer de próstata?

Posibles riesgos si se hace las pruebas:

- Su nivel de PSA puede ser bajo, aún si hay cáncer presente.
- Usted puede preocuparse por los resultados.
- Hacerse las pruebas puede detectar un cáncer que tal vez nunca le hubiera causado problemas.
- Hacerse las pruebas puede resultar en tratamiento y los efectos secundarios del tratamiento. Estos incluyen problemas para controlar la orina, problemas con los intestinos, y problemas sexuales.

¿Qué pasa si <u>no me hago</u> las pruebas de detección de cáncer de próstata?

A usted le hacen sus chequeos médicos regulares pero no las pruebas de detección de cáncer de próstata.

Usted puede cambiar de opinión y hacerse las pruebas en el futuro.

Posibles beneficios si <u>no se hace</u> las pruebas:

- Evita la preocupación que podría sentir a causa de las pruebas.
- Evita recibir tratamiento para un cáncer que quizá nunca le hubiera causado problemas.
- Evita los efectos secundarios que se pueden presentar con el tratamiento.

¿Qué pasa si <u>no me hago</u> las pruebas de detección de cáncer de próstata?

Posibles riesgos si no se hace las pruebas:

- Usted pudiera tener un cáncer de próstata en una etapa inicial y no saberlo.
- Usted pudiera tener un cáncer de próstata que más adelante le causará síntomas o acortará su vida, y pudiera no tener oportunidad de encontrarlo a tiempo.

¿Cómo decido si las pruebas de detección son la mejor opción para mí?

Evalúe sus opciones y decida lo que es importante para usted.

- Hay muchas razones por las que los hombres deciden hacerse o no las pruebas de detección de cáncer de próstata.
- Algunas razones están enlistadas en la siguiente diapositiva.
- Reflexione en cuáles de estas razones son importantes para usted.

La decisión es suya.

En esta área, el médico no es el único experto. Conozca los hechos y usted podrá decidir si hacerse las pruebas es importante para usted.



¿Qué es mas importante para usted... A o B?

A. Algunas razones por las que un hombre puede decidir a hacerse las pruebas:	B. Algunas razones por las que un hombre puede decidir a no hacerse las pruebas:
Estaré tranquilo cuando sepa los resultados de las pruebas.	Me voy a preocupar acerca de los resultados de las pruebas.
Sabré si tengo cáncer de próstata o no.	Pudiera encontrar un cáncer de próstata que tal vez nunca me cause problemas ni acorte mi vida.
Tengo una mejor oportunidad de obtener un tratamiento para el cáncer si se detecta tempranamente.	Si se detecta cáncer tal vez tendría que lidiar con el tratamiento y los efectos secundarios.



Usted puede desear hacerse las pruebas si:

- Usted valora el encontrar el cáncer tempranamente
- Usted está dispuesto a ser tratado aún sin tener un beneficio asegurado
- Usted está dispuesto a correr el riesgo de un daño urinario, sexual o intestinal causado por el tratamiento de cáncer de próstata, tales como cirugía y radiación.

Usted puede desear no hacerse las pruebas si:

- Usted le da más valor a evitar los riesgos causados por las pruebas y el tratamiento, tales como preocupaciones o problemas urinarios, sexuales e intestinales
- Usted está dispuesto a aceptar la posibilidad de que pudiera tener cáncer de próstata y no saberlo antes de que le cause algún daño

¿Qué recomienda la Sociedad Americana Contra el Cáncer?

La Sociedad Americana Contra el Cáncer recomienda que todos los hombres tomen una decisión informada acerca de las pruebas de detección.

A partir de los 50 años de edad, hable con su médico o consejero médico acerca de las pruebas para detectar el cáncer de próstata y su tratamiento.

- Usted debe evaluar los riesgos y los posibles beneficios;
- Piense en lo que es importante para usted;
- Luego debería decidir si hacerse las pruebas es la mejor opción para usted.

¿Qué recomienda la Sociedad Americana Contra el Cáncer?

- Si usted es de raza negra o tiene un padre o hermano que haya padecido cáncer de próstata antes de los 65 años, comience este diálogo con su médico desde los 45 años.
- Los hombres con 2 o más parientes cercanos que hayan padecido de cáncer de próstata a una edad temprana deberían comenzar esta plática al cumplir los 40 años.
- Si usted decide hacerse las pruebas, debe tomar la prueba de sangre PSA con o sin examen rectal. La frecuencia de las pruebas dependerá de su nivel de PSA.

¿Ahora qué debo hacer?

- Hable con su médico acerca de las pruebas de detección.
- Piense en lo que es importante para usted.
- Decida qué es lo mejor para usted y su familia.



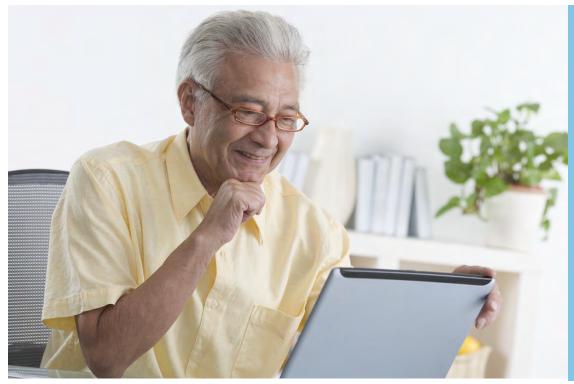
¿Dónde puedo conseguir más información para ayudarme a decidir?

- La Sociedad Americana Contra el Cáncer 1-800-227-2345
 - http://www.cancer.org/Espanol/cancer/Cancerdeprostata/index
- Centros para el Control y la Prevención de Enfermedades de los Estados Unidos
- La Clínica Mayo
- La Fundación Para la Toma de Decisiones Médicas Informadas

Para mayor información sobre cáncer, preguntas, y apoyo, llame a La Sociedad Americana Contra el Cáncer las 24 horas del día, los 7 días de la semana al 1-800-227-2345.



Pruebas de detección del cáncer de próstata



"¿Debería hacerme las pruebas?

"La decisión es mía."





El cáncer de próstata afecta a muchos hombres.

Existen pruebas para encontrarlo temprano.

Esta información le ayudará a decidir si usted quiere hacerse las pruebas de detección de cáncer de próstata.



- Puede haber tanto beneficios como riesgos con las pruebas de detección y el tratamiento para cáncer de próstata.
- Las investigaciones aún no han demostrado que los beneficios son mayores que los riesgos.

"Detección" significa buscar cáncer **antes** de tener síntomas.



- Aquí hablaremos más sobre el cáncer de próstata y los posibles beneficios y riesgos de las pruebas de detección y el tratamiento.
- Después de ver esta presentación, esperamos que usted pueda decidir si quiere hacerse o no las pruebas de detección.
- Si tiene otras preguntas después de ver esta presentación, por favor hable con su médico o consejero médico.

¿Qué debo hacer si tengo síntomas de la próstata?

La información de esta presentación es para ayudar a hombres que no tienen síntomas de la próstata a decidir si quieren hacerse las pruebas de detección.

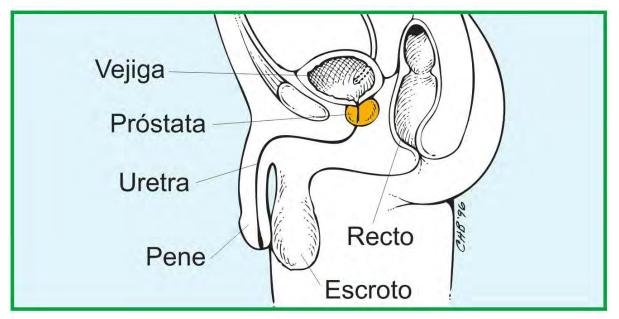
Hable con un médico inmediatamente si tiene:

- problemas al orinar,
- sangre en la orina, o
- dolor al orinar

Estos síntomas a menudo son causa de otros problemas de la próstata, pero también pueden ser causados por el cáncer de próstata. La única manera de saber lo que está mal es consultar un médico.

¿Qué es el cáncer de próstata?

- El cáncer comienza en su cuerpo cuando células normales empiezan a crecer sin control.
- En el cáncer de próstata, las células de la próstata crecen sin control.
- Las células de cáncer se pueden propagar y afectar órganos cercanos.
 También se pueden propagar a partes distantes del cuerpo y causar problemas.





El cáncer de próstata puede causar la muerte, pero no todos los casos de cáncer de próstata son iguales.

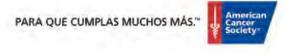
- Muchos casos de cáncer de próstata crecen lentamente.
 Por lo general, si no son tratados, estos cánceres pueden no causar problemas por muchos años.
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Pruebas de detección del cáncer de próstata



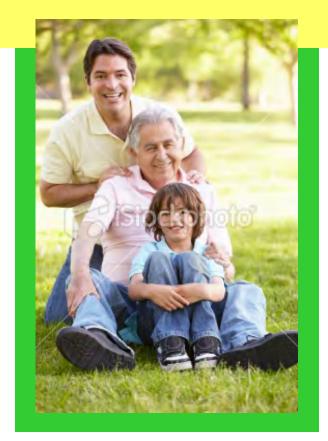
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Existen pruebas para encontrarlo temprano.



Esta información le ayudará a decidir si usted quiere hacerse las pruebas de detección de cáncer de próstata.

¿Son las pruebas de detección la mejor opción para mí?

- Puede haber tanto beneficios como riesgos con las pruebas de detección y el tratamiento para cáncer de próstata.
- Las investigaciones no han comprobado todavía que los beneficios son mayores que los riesgos.

"Detección" significa buscar cáncer **antes** de tener síntomas.



¿Son las pruebas de detección la mejor opción para mí?

- Aquí hablaremos más sobre el cáncer de próstata y los posibles beneficios y riesgos de las pruebas de detección y del tratamiento.
- Después de ver esta presentación, esperamos que usted pueda decidir si quiere hacerse o no las pruebas de detección.
- Si tiene otras preguntas después de ver esta presentación, por favor hable con su médico o consejero médico.

¿Qué debo hacer si tengo síntomas de la próstata?

La información de esta presentación es para ayudar a hombres que no tienen síntomas de la próstata a decidir si quieren hacerse las pruebas de detección.

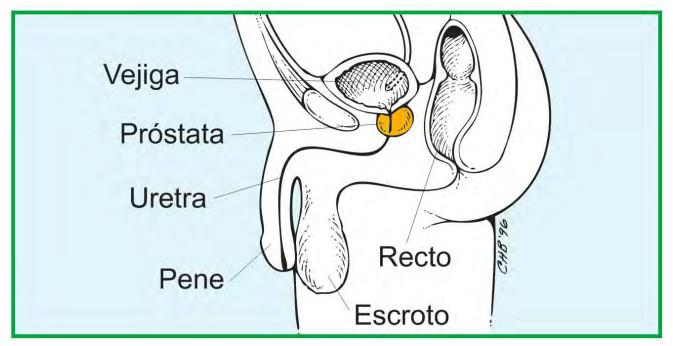
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¿Son iguales todos los casos de cáncer de próstata?

El cáncer de próstata puede causar la muerte. Pero no todos los tipos de cáncer de próstata son iguales.

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 Por lo general, si no son tratados, estos cánceres pueden no causar problemas por muchos años.
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Pruebas de detección del cáncer de próstata

"¿Debería hacerme las pruebas?"

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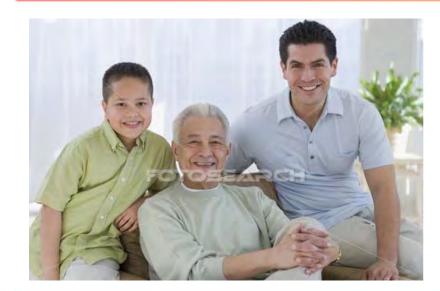




El cáncer de próstata afecta a muchos hombres.

Existen pruebas para detectarlo temprano.





Esta información le ayudará a decidir si usted quiere hacerse las pruebas de detección de cáncer de próstata.



¿Son las pruebas de detección la mejor opción para mi?

- Puede haber tanto beneficios como riesgos con las pruebas de detección y el tratamiento para cáncer de próstata.
- Las investigaciones no han comprobado todavía que los beneficios son mayores que los riesgos.

"Detección" significa buscar cáncer **antes** de tener síntomas.

¿Son las pruebas de detección la mejor opción para mi?

- Aquí hablaremos más sobre el cáncer de próstata y los posibles beneficios y riesgos de las pruebas de detección y el tratamiento.
- Después de ver esta presentación, esperamos que usted pueda decidir si quiere hacerse o no las pruebas de detección.
- Si tiene otras preguntas después de ver esta presentación, por favor hable con su médico o consejero médico.



¿Qué debo hacer si tengo síntomas de la próstata?

La información de esta presentación es para ayudar a hombres que no tienen síntomas de la próstata a decidir si quieren hacerse las pruebas de detección.

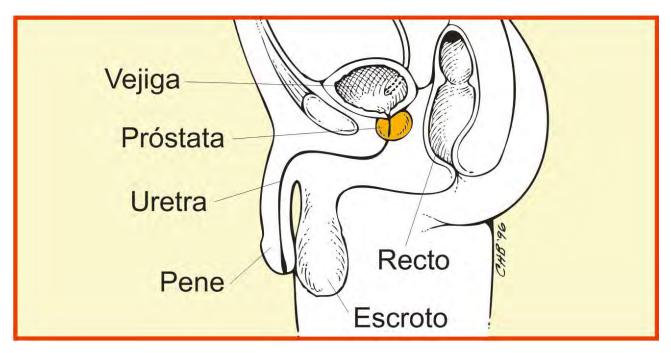
Hable con un médico inmediatamente si tiene:

- problemas al orinar,
- sangre en la orina, o
- dolor al orinar

Estos síntomas a menudo son causa de otros problemas de la próstata, pero también pueden ser causados por el cáncer de próstata. La única manera de saber lo que está mal es consultar un médico.

¿Qué es el cáncer de próstata?

- El cáncer comienza en su cuerpo cuando células normales empiezan a crecer sin control.
- En el cáncer de próstata, las células de la próstata crecen sin control.
- Las células de cáncer se pueden propagar y afectar órganos cercanos. También se pueden propagar a partes distantes del cuerpo y causar problemas.





¿Son iguales todos los casos de cáncer de próstata?

El cáncer de próstata puede causar la muerte, pero no todos los casos de cáncer de próstata son iguales.

- Muchos casos de cáncer de próstata crecen lentamente. Por lo general, si no son tratados, estos cánceres pueden no causar problemas por muchos años.
- Algunos casos de cáncer de próstata son más agresivos y crecen rápidamente. Éstos pueden propagarse a otras partes del cuerpo, donde pueden causar dolor intenso y otros problemas, e incluso pueden causar la muerte.



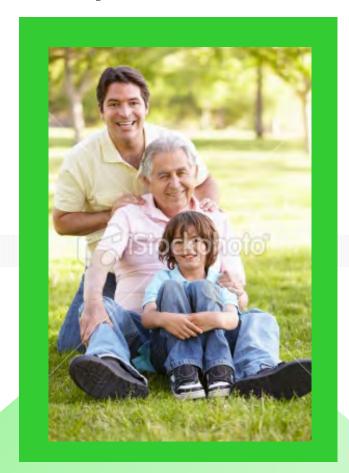
Pruebas de detección del cáncer de próstata

"¿Deberia hacerme las pruebas?"



"La decisión es mía."

El cáncer de próstata afecta a muchos hombres. Existen pruebas para encontrarlo temprano.



Esta información le ayudará a decidir si usted quiere hacerse las pruebas de detección de cáncer de próstata.

¿Son las pruebas de detección la mejor opción para mí?



- Puede haber tanto beneficios como riesgos con las pruebas de detección y el tratamiento para cáncer de próstata.
- Las investigaciones no han comprobado todavía que los beneficios son mayores que los riesgos.

[&]quot;Detección" significa buscar cáncer antes de tener síntomas.

COGNITIVE TESTING: INTERVIEW GUIDE ENTREVISTA COGNOSCITIVA: GUÍA DE LA ENTREVISTA

Número del Participante:	
Fecha:	Hora:
Instrucciones al entrev <i>La escritura que se leer</i>	vistador están en impresión oscura. á esta en itálicos.

Función 1: Introducción/Propósito del Estudio

Task 1: Introduction/Purpose of the Study

Gracias por su interés en este estudio. La razón que hoy estamos hablando con usted es que queremos probar el texto y los gráficos para una ayuda de decisión sobre las pruebas de detección del cáncer de próstata. Queremos asegurarnos que son fáciles de entender. Usaremos la información que usted nos dé para crear una presentación educativa que ayudara a hombres que están considerando hacerse las pruebas para encontrar el cáncer de próstata a tomar decisiones informadas.

Primero, voy a revisar el consentimiento informado, la autorización para participar en este estudio de investigación, para estar seguro(a) que usted entiende el propósito del estudio. Entonces, le preguntare si usted tiene algunas preguntas o preocupaciones sobre el estudio.

Después de que se contesten sus preguntas, le pediré que complete el consentimiento informado. Ya que terminemos el proceso del consentimiento, le pediré que complete un cuestionario demográfico general. Entonces comenzaremos le entrevista donde le hare preguntas acerca de los materiales educativos.

Función 2: Proceso del Consentimiento Informado

Task 2: Informed Consent Process

Revise el consentimiento informado con el participante. Pregunte si él tiene alguna pregunta. Conteste cualquier pregunta que él tenga. Si el está de acuerdo, pida que firme y que le ponga la fecha en la forma del consentimiento. No olvide que también necesita una persona no asociada con el estudio que firme y que ponga la fecha en la forma del consentimiento como testigo. Asegure que el participante (y usted) marque si el eligió o no eligió a el procedimiento opcional. También firma y ponga la fecha como la persona que está obteniendo el consentimiento y asegura de dar una copia al participante para guardar. Incluso termine la documentación del consentimiento informado.

Función 3: Cuestionario Demográfico

Task 3: Demographic Questionnaire

Ahora, le haré algunas preguntas demográficas generales. Esto tardará menos de 5 minutos. Pide a los participantes que terminen el cuestionario demográfico. Recoge el cuestionario completado. Gracias por terminar el cuestionario demográfico.

Función 4: Entrevista Cognosctiva

Task 4: Cognitive Interview

La meta aquí es obtener una mejor idea si lo escrito y los gráficos de nuestros materiales son claros para entender. Quiero que piense en voz alta mientras procedemos. Entonces, mientras mire los gráficos y este leyendo - dígame todo lo que esté pensando.

De vez en cuando pararé y le haré preguntas acerca de ciertas palabras o de ciertas frases. También estaré tomando notas al mismo tiempo.

Por favor tome en cuenta que realmente quiero escuchar todas sus opiniones y reacciones. No se detenga para protestar si algo le parece confuso o es en cualquier momento difícil de contestar.

Haremos esto por una hora, a menos de que ya no tenga preguntas para usted antes de que alcancemos la hora.

¿Antes de que comencemos, tiene usted alguna pregunta? Conteste cualquier pregunta que él tenga.

Empieza la Entrevista

Begin Cognitive Interview

Muestre al participante la presentación educativa adaptada, una pantalla a la vez. Para cada pantalla, pregunte las siguientes preguntas y haga nota de las repuestas verbales y no verbales.

Preguntas:

Questions:

1.	¿Por favor dígame en sus propias palabras qué significa esta informacíon [o gráfico] para usted?
2.	¿Por favor dígame lo que pensaba cuando vio la pantalla?
3.	¿Encontró la informacion en la pantalla fácil o difícil de entender? ¿De que modo?
4.	¿Por favor dígame su nivel de comodidad mientras miraba la pantalla? ¿Estuvo cómodo? ¿De que modo?
5.	¿Cómo le ayudo el gráfico a entender lo que está escrito?
6.	¿Hay algo qué encontró confuso, muy claro, o menos claro?

Otras puntas de prueba adicionales que puedan ser nesesarias: Additional questions if necessary:

Pregunta Adicional 1		
¿Noté que usted vaciló antes de conte	estar — de que estaba pensando?	?
Pregunta Adicional 2		
Pregunta Adicional 3		
Comentarios: • Notice respondents behavior like non understanding	-verbal cues, discomfort, hesitati	on or lack of
Notice response latency: time elapsed of a response	l between the presentation of que	estion and the indication
Cualquier otro comentarios		
Eso concluye nuestra entrevista. ¡Gracias p por su tiempo! * No olvide obtener firma en la form compensación.		ŭ
	/ /	☐ am : ☐ pm
PI or Delegate Signature	Date	Time
PI or Delegate Printed Name	PI or Delegate Er	mployee ID#

AIM 2 - COGNITIVE TESTING: INTERVIEW GUIDE

Patient ID Number:		
Date:	Time:	
Instructions to intervie	wer are in bold. Script to be read is in italics.	

Task 1: Introduction/Purpose of the Study

Thank you for your interest in this study. The reason we are talking with you today is that we would like test the wording and graphics for a decision aid about prostate cancer screening. We want to make sure these are easy for people to understand. We will use the information to create an educational presentation that helps Spanish-speaking men who are considering being tested for prostate cancer make an informed decision.

First, I am going to review the informed consent form to you to be sure that you understand what the study is about. Next, I will ask if you have any questions or concerns about this study. Once your questions are answered, I will ask you to complete an informed consent form. After we complete the consent process, I'll ask you to complete general demographic questionnaire. Then we will begin the interview where I will be asking you some questions about educational materials.

Task 2: Informed Consent Process

Go over the informed consent form with the participant. Ask if he has any questions. Answer any questions he has. If he agrees, have him sign and date the consent form. Do not forget to have a witness that is not associated with the study sign and date. Make sure that the participant (and you) indicated if they elect or do not elect to the optional procedure. Sign and date it as the person obtaining consent, and give the participant a copy to keep. Also complete the informed consent documentation.

Task 3: Demographic Questionnaire

Now, let's go over some general demographic questions. This will take less than 5 minutes. Ask the participants to complete the Demographic Questionnaire. Collect the completed questionnaire. Thank you for completing the demographic questionnaire.

Task 4: Cognitive Interview

The goal here is to get a better idea if the wording and graphics of our materials are understandable. I'd like you to think aloud as we go. So as you look at the graphics and read through the text – just tell me everything you are thinking.

At times I will stop and ask you more questions about the terms or phrases used. I will be also taking notes at the same time.

Please keep in mind that I really want to hear all of your opinions and reactions. Don't hesitate to speak up whenever something seems unclear or is hard to answer.

We will do this for an hour, unless I run out of things to ask you before then.

Do you have any questions before we start? Answer any questions.

Show participants the adapted slide set, one slide at a time. For each slide, ask from the following set of questions and note verbal and non-verbal responses.

Questi	ons:	
1.	Please tell me in your own words what the text [or graphic] is showing.	
2.	Tell me what you were thinking when you saw this slide.	
3.	Was this slide easy or difficult to understand? How so?	
4.	Were you comfortable viewing this slide? How so?	
5.	How does the text help you understand the graphic?	
6.	Is there anything that was unclear?	
Add a	ny additional probes that may be needed.	
Promp	ting Question 1	
•	I noticed you hesitated before you answered—what were you thinking about?	
Promp	ting Question 2	

	compensation forms, provide the participants orm.	,,,
ludes our interview. Thank you fo	or sharing your thoughts and thank you very mu	ch for
ny other comments		
otice response latency: time elapse dication of a response	ed between the presentation of question and the	
s: otice respondents behavior like no derstanding	on-verbal cues, discomfort, hesitation or lack of	
g Question 3		
	otice respondents behavior like not derstanding otice response latency: time elapse lication of a response	s: otice respondents behavior like non-verbal cues, discomfort, hesitation or lack of derstanding otice response latency: time elapsed between the presentation of question and the lication of a response

AIM 3 - EVALUATION: FOCUS GROUP GUIDE GRUPO DE ENFOQUE - GUÍA DE LA EVALUACIÓN

Número del Parti	pante:	
Fecha:	Hora:	
Instrucciones a	entrevistador están en impresión oscura	a.
La escritura aue	se leerá esta en itálicos.	

Función 1: Introducción/Propósito del Estudio

Task 1: Introduction/Purpose of the Study

Gracias por su interés en este estudio. La razón que hoy estamos hablando con usted es que queremos mostrarle una presentación educativa sobre las pruebas de detección del cáncer de próstata y pedirle que nos diga su opinión y también saber que aprendió de la presentación por medio de unos cuestionarios. Usaremos la información que usted nos de para asistirnos a crear una ayuda de decisión que ayudará a hombres que están considerando hacerse las pruebas para encontrar el cáncer de próstata a tomar una decisión informada.

Primero, voy a revisar el consentimiento informado, la autorización para participar en este estudio de investigación, para estar seguro(a) que usted entiende el propósito del estudio. Entonces, le preguntaré si usted tiene algunas preguntas o preocupaciones sobre el estudio. Después de que se contesten sus preguntas, le pediré que complete el consentimiento informado y obtendremos su firma y fecha en la forma del consentimiento. Ya que terminemos el proceso del consentimiento, le pediré que complete un cuestionario demográfico general y un cuestionario sobre el cáncer de próstata. Luego comenzaremos a revisar la presentación educativa como un grupo. Después, le haré preguntas acerca de lo que usted pensó de la presentación educativa y los materiales, y también le pediré que complete otro cuestionario sobre el cáncer de próstata.

Función 2: Proceso del Consentimiento Informado

Task 2: Informed Consent Process

Revise el consentimiento informado con el participante. Pregunte si él tiene alguna pregunta. Conteste cualquier pregunta que él tenga. Si el está de acuerdo, pida que firme y que le ponga la fecha en la forma del consentimiento. Asegure que el participante (y usted) marque si el eligió o no eligió a el procedimiento opcional. También firma y ponga la fecha como la persona que está obteniendo el consentimiento y asegura de dar una copia al participante para guardar. Incluso termine la documentación del consentimiento informado.

Función 3: Cuestionario Demográfico

Task 3: Demographic Questionnaire

Ahora, le haré algunas preguntas demográficas generales. Esto tardará menos de 5 minutos. Pide que el participante termine el Cuestionario Demográfico. Recoge el cuestionario completado. Gracias por terminar el Cuestionario Demográfico.

Función 4: CUESTIONARIO – Prueba Inicial

Task 4: Pre-test Questionnaire

En este momento, le voy hacer algunas preguntas sobre cáncer de próstata por medio de un cuestionario. Pide que el participante termine el Cuestionario de Prueba Inicial. Recoge el cuestionario completado. Gracias por terminar el Cuestionario de Prueba Inicial.

Función 5: Revise y Muestre la Presentación Educativa Adaptada Task 5: Review of Adapted Slide Set

Ahora, vamos a revisar la presentación educativa sobre el cáncer de próstata. Algunos de nosotros estaremos tomando notas durante la discusión.

Estamos haciendo esta discusión en modo de grupo, así podrán compartir sus ideas y preguntas y responder a los pensamientos y a las experiencias de otros. Todo comentarios, positivo y negativo, bueno y malo, serán agradecidas.

Deje que cada persona se introduzca por su nombre (sin apellido o por otro nombre que él quiera usar para esta discusión). Revise y muestre la presentación educativa adaptada con el grupo. *Gracias por su atención a la presentación educativa*.

<u>Función 6: CUESTIONARIO – Prueba Posterior</u> Task 6: Post-test Questionnaire

Ahora, le vamos hacer algunas preguntas por medio de un último cuestionario. Pide que el participante termine el Cuestionario de Prueba Posterior. Recoge el cuestionario completado. Gracias por terminar el Cuestionario de Prueba Posterior.

Eso concluye nuestro grupo de enfoque de hoy. ¡Gracias por compartir sus pensamientos y le agradecemos mucho por su tiempo!

* No olvide obtener firma en la forma de compensación y provea el participante con la compensación.

		□ am :□ pm
PI or Delegate Signature	Date	Time
PI or Delegate Printed Name	PI or Delegate Em	ployee ID#

CUESTIONARIO DEMOGRAFICO

Por favor conteste las siguientes preguntas e indique sus respuestas con una X al lado de la respuesta que le describe mejor o escribiendo su respuesta en el espacio en blanco. Estas preguntas serán utilizadas solamente para uso en este estudio de investigación y sus repuestas serán mantenidas estrictamente confidenciales.

1.	¿Cuál es su o	edad?			
	Año	S			
2.	¿Cuál es su 1	raza o grupo étr	nico? (Indique to	odas las opcion	es aplicables)
			nativo de Alaska		Asiático
		ro no hispano			Hispano o Latino
					Blano no hispano
	Otra	raza (especifiq	ue):		
3.	¿Cuál es su l	lengua materna	?		
	Ingle	és	Otra	(especifique):	
	Espa			\ 1	
	.	14 10			
4.	¿En qué país	s nació usted?			
	Esta	dos Unidos	Otra	(especifique): _	
	Méx	tico			
5.	¿Cuál es el n	nivel/año de esc	uela más alto qı	ue usted ha com	npletado?
	Escuela	Escuela	Escuela	Universidad	Posgraduado
	Primaria	Secundaria	Preparatoria		
	01	06	09	13	17
	02	07	10	14	18
	03	08	11	15	
	04		12	16	20 +
	05				
6.	¿Cuál es su e	estado civil actu	ıal?		
	Solte	ero			
			ación a largo pl	azo	
	Divo	orciado	<i>C</i> 1		
	Viu				
	Otra	(especifique):			

Т	Delegate Printed Name	PI or Delegate Employee ID#
or D	Delegate Signature	Date and Time
	Prefiero dejar todas las decisions	s a mi doctor.
	-	ecisión final después de considerar seriamente mi opinion
		sponsibilidad de la decisión final.
		lespués de considerar seriamente la opinión de mi docto
	Prefiero tomar la decisión final.	
11.	decisiones acerca de la las pruebas de	raciones que describe mejor cómo usted prefiere toma: detección del cáncer de próstata?
	No	
	Sí	
10.). ¿Alguna vez le han hecho una biopsia	de la próstata?
	Nunca me he hecho una prueb	oa de PSA
	No	1 704
	Sí	
9.	¿Conoce usted su resultado mas recier	nte de la prueba PSA?
	No	
	Sí	
8.	¿Ha oído usted de la prueba PSA (por la prueba antígeno prostático específic	sus siglas en ingles) también se conoce como APE o co?
	ivo estoy seguio	
	No No estoy seguro	
	Sí - algún otro pariente	

<u>AIM 3 - EVALUATION: PRE-TEST QUESTIONNAIRE</u> Cuestionario de Prueba Inicial

Número del Participante:

	Fecha:				
	Aquí hay algunas preguntas sobre cáncer de próstata. F de cada pregunta. Si usted no está seguro de la respues estoy seguro".	_			
			Sí	No	No estoy seguro
1.	¿Hay algunos hombres que nunca sabrán que tienen cáncer o	le próstata?	[]	[]	[]
2.	¿Serán la mayoría de los hombres diagnosticados con el cáncurso de sus vidas?	cer de próstata en e	el []	[]	[]
3.	¿La prueba PSA (por sus siglas en inglés - también se conoc significa Antígeno Prostático Especifico en español) una p detectar el cáncer de próstata?			[]	[]
4.	¿El tratamiento para el cáncer de próstata puede resultar en p controlar la orina?	problemas de	[]	[]	[]
5.	¿Tienen las mujeres próstatas?		[]	[]	[]
6.	¿Si se detecta el cáncer de próstata tempranamente, usualme	nte es curable?	[]	[]	[]
7.	¿El riesgo de desarrollar cáncer de próstata, para un hombre,	aumenta con la eda	d? []	[]	[]
8.	¿El tratamiento para el cáncer de próstata puede resultar en p	oroblemas sexuales	s? []	[]	[]
9.	¿Los hombres de raza negra corren menos riesgo de desarrol que otros hombres?	lar cáncer de prósi	ata []	[]	[]
10.	¿Los hombres que tienen alguien en su familia diagnosticado próstata tienen un riesgo más alto de desarrollar cáncer de processor de la composição de la compos		[]	[]	[]
11.	¿Es necesaria una biopsia para determinar si un hombre tiene	e cáncer de próstat	a? []	[]	[]
12.	¿Las pruebas de detección incluye tener un examen rectal?		[]	[]	[]
13.	¿Podría morir un hombre de cáncer de próstata si se ha propadel cuerpo?	agado a otras parte	s []	[]	[]
14.	¿La cirugía es el único tratamiento para el cáncer de próstata	1?	[]	[]	[]
15.	¿Un nivel alto del PSA significa que un hombre tiene cáncer	de próstata?	[]	[]	[]
16.	¿Son iguales todos los casos de cáncer de próstata?		[]	[]	[]
				:_	□ am □ pm
	PI or Delegate Signature	Date	Time		
	PI or Delegate Printed Name	PI or Delegate Em	ployee ID#		

AIM 3 - EVALUATION: POST-TEST QUESTIONNAIRE CUESTIONARIO – PRUEBA POSTERIOR

Nún	nero del Participante:
Fech	ha: Hora:
pres	uí hay algunas preguntas sobre la presentación educativa y lo que usted pensó de la sentación. Por favor indique (√) una respuesta al lado de cada pregunta. Esta información ayudará a evaluar la presentación de las pruebas para el cáncer de próstata.
1. ¿	¿Cómo calificaría la cantidad de información ofrecida en la presentación?
	 [] Mucho menos que quería [] Un poco menos que quería [] Uno poco más que quería [] Mucho más que quería
2. ¿	¿Cómo calificaría la cantidad de tiempo para completar la presentación? [] Demasiado largo
	[] Un poco largo
	[] Apropiada
	[] Debería haber sido un poco más largo[] Debería haber sido mucho más largo
3. ¿	¿Con qué claridad se presentaron los temas discutidos en la presentación?
	[] Todo fue claro
	[] La mayoría de la información fue clara
	[] Cierta información no fue clara
	[] La mayoría de la información no fue clara
4. ¿	Coma calificaría el equilibrio de los temas cubiertos en la presentación?
	[] Favorece claramente hacerse las pruebas de detección
	[] Favorece un poco hacerse las pruebas de detección
	[] Equilibrado[] Favorece un poco no hacerse las pruebas de detección
	[] Favorece claramente no hacerse las pruebas de detección

5.	¿Recomendaría usted esta presentación a otras personas que estén enfrentando esta decisión?
	[] Sí [] No [] No estoy seguro
6.	¿Le pareció interesante la presentación que vio?
	[] Sí [] No [] No estoy seguro
7.	¿Le ayudo la presentación que vio le a entender las pruebas de detección del cáncer de próstata?
	[] Sí [] No [] No estoy seguro
8.	¿La presentación que vio le dio información que encontró útil?
	[] Sí [] No [] No estoy seguro
9.	¿La presentación utilizó un lenguaje que usted entendió?
	[] Sí [] No [] No estoy seguro
10	. ¿Le gustaría hacer preguntas acerca de lo que vio?
	[] Sí [] No [] No estoy seguro
11	. ¿Sintió que la presentación estaba dirigido a usted y personas como usted?
	[] Sí [] No [] No estoy seguro

Aquí hay algunas preguntas sobre cáncer de próstata. Por favor indique (\checkmark) una respuesta al lado de cada pregunta. Si usted no está seguro de la respuesta a una pregunta, por favor indique "No estoy seguro".

		Sí	No	No estoy seguro
1.	¿Hay algunos hombres que nunca sabrán que tienen cáncer de próstata?	[]	[]	[]
2.	¿Serán la mayoría de los hombres diagnosticados con el cáncer de próstata en el curso de sus vidas?	[]	[]	[]
3.	¿La prueba PSA (por sus siglas en inglés - también se conoce como APE - APE significa Antígeno Prostático Especifico en español) una prueba de sangre para detectar el cáncer de próstata?	[]	[]	[]
4.	¿El tratamiento para el cáncer de próstata puede resultar en problemas de controlar la orina?	[]	[]	[]
5.	¿Tienen las mujeres próstatas?	[]	[]	[]
6.	¿Si se detecta el cáncer de próstata tempranamente, usualmente es curable?	[]	[]	[]
7.	¿El riesgo de desarrollar cáncer de próstata, para un hombre, aumenta con la edad?	[]	[]	[]
8.	¿El tratamiento para el cáncer de próstata puede resultar en problemas sexuales?	[]	[]	[]
9.	¿Los hombres de raza negra corren menos riesgo de desarrollar cáncer de próstata que otros hombres?	[]	[]	[]
10.	¿Los hombres que tienen alguien en su familia diagnosticados con cáncer de próstata tienen un riesgo más alto de desarrollar cáncer de próstata?	[]	[]	[]
11.	¿Es necesaria una biopsia para determinar si un hombre tiene cáncer de próstata?	[]	[]	[]
12.	¿Las pruebas de detección incluye tener un examen rectal?	[]	[]	[]
13.	¿Podría morir un hombre de cáncer de próstata si se ha propagado a otras partes del cuerpo?	[]	[]	[]
14.	¿La cirugía es el único tratamiento para el cáncer de próstata?	[]	[]	[]
15.	¿Un nivel alto del PSA significa que un hombre tiene cáncer de próstata?	[]	[]	[]
16.	Son iguales todos los casos de cáncer de próstata?	Г 1	ſ 1	[]

¿Cuáles son sus pensamientos o preferencias acerca de la pruebas de detección para el cáncer de próstata?

		Sí	No	No esto
1.	¿Sabe cuáles opciones están disponibles para usted?	[]	[]	[]
2.	¿Sabe cuáles son los beneficios de cada opción?	[]	[]	[]
3.	¿Sabe los riesgos y los efectos secundarios de cada opción?	[]	[]	[]
4.	¿Tiene claro cuales beneficios son más importantes para usted?	[]	[]	[]
5.	¿Tiene claro cuales riesgos y efectos secundarios son más importantes para usted?	[]	[]	[]
6.	¿Tiene suficiente apoyo de otras personas para tomar una decisión?	[]	[]	[]
7.	¿Está escogiendo sin que lo presionen otras personas?	[]	[]	[]
8.	¿Le han aconsejado lo suficiente para tomar una decisión?	[]	[]	[]
9.	¿Tiene claro cuál es la mejor opción para usted?	[]	[]	[]
10	¿Se siente seguro sobre que opción elegir?	[]	[]	[]
10.	Finalmente, por favor díganos lo que usted piensa de las siguientes	pregi	ıntas.	
10.	Finalmente, por favor díganos lo que usted piensa de las siguientes prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse has pruebas de detección para el cáncer de prima la intención de hacerse de prima la intención de hacerse de prima la intención de detección para el cáncer de prima la intención de la intención de			
10.	1. ¿Tiene la intención de hacerse has pruebas de detección para el cáncer de j [] Sí [] No			

4. ¿Si usted perdería su capacidad de tener Sería	r una erección, que significaría eso para usted?
[] Tan serio que pueda ser que nur[] Serio, pero me ajustaría[] Un ajusto menor para mí	nca ajustaría
Por favor regrese este formulario	o cuando lo ha terminado.
Eso concluye su participación en nues	stro estudio
¡Gracias por compartir sus pensamien	ntos y le agradecemos mucho por su tiempo!
PI or Delegate Signature	Date and Time
PI or Delegate Printed Name	PI or Delegate Employee ID#

AIM 3 - EVALUATION: FOCUS GROUP GUIDE

Instructions to interviewer are in bold. *Script to be read is in italics.*

Task 1: Introduction/Purpose of the Study

Thank you for your interest in this study. The reason we are talking with you today is that we would like show you a slide set about prostate cancer screening and see what you think about it and what you learn from it. The information you give us will help us create decision aid which will help men who are considering being tested for prostate cancer.

First, I am going to review the informed consent form to you to be sure that you understand what the study is about. Next, I will ask if you have any questions or concerns about this study. Once your questions are answered, I will ask you to complete an informed consent form. After we complete the consent process, I'll ask you to complete general demographic questionnaire and a questionnaire about prostate cancer. Then we will review a slide set as a group. Afterwards, I'll ask questions about what you thought of the materials and ask some more questions about prostate cancer.

Task 2: Informed Consent Process

Go over the informed consent form with the participants. Ask them if they have any questions. Answer any questions they have. If they agree, have them sign and date the consent form. Sign and date it as the person obtaining consent, and give the participant a copy to keep. Also complete the informed consent documentation.

Task 3: Demographic Questionnaire

Now, let's go over some general demographic questions. This will take less than 5 minutes. Ask the participants to complete the Demographic Questionnaire. Collect the completed questionnaire. Thank you for completing the demographic questionnaire.

Task 4: Pre-test Questionnaire

Next, we are go through some questions about prostate cancer. Ask the participants to complete the Pre-test Questionnaire. Collect the completed questionnaire. Thank you for completing the questionnaire.

Task 5: Review of Adapted Slide Set

Now, we are going to review the slide set about prostate cancer. With your permission, we would like to record the discussion. We are recording so that we can really pay attention to what you are saying instead of having to spend time taking notes.

So that we can protect the privacy of the discussion today, I'm going to ask that we use first names only. All names and personal information you provide will be kept strictly confidential. In fact, you do not even need to use your real name if you prefer.

Because we are recording the session and we want to get input from everyone, please speak one at a time so the tape recorder can pick up everyone's comments. I'm going to turn the recorders on now. **Turn on the recorders.**

We are doing this group discussion so that people can share their ideas and questions and respond to the thoughts and experiences of others. All comments, positive and negative, good and bad, are welcome.

Have each person introduce himself by first name (or another name that he wants to use for this discussion). Review the adapted slide set with the group. *Thank you for attention to the slideset.* Turn off the recorders.

Task 6: Post-test Questionnaire

Now we are going to do one more questionnaire. Ask the participants to complete the Posttest Questionnaire. Collect the completed questionnaire. Thank you for completing the questionnaire.

That concludes today's group. Thank you very much for your time!

Provide the participants' compensation.

DEMOGRAPHIC QUESTIONNAIRE

Please complete these questions by marking an X next to the answer that best describes you or by filling in the blank. These questions are for research purposes only and your answers will be kept strictly confidential.

1.	How old are you?					
	Years					
2.	What is your race or ethnicity? Please check all that apply.					
	American Indian or Alaska NativeAsianBlack not HispanicHispanic or LatinoNative Hawaiian or Other Pacific IslanderWhite not HispanicOther (please specify):					
3.	What is your primary language?					
	English Other (please specify): Spanish					
4.	In what country were you born? United States Other (please specify): Mexico					
5.	What is the highest grade/level of education that you have completed?					
	Elementary Middle High College Graduate School School School 01 06 09 13 17 02 07 10 14 18 03 08 11 15 19 04 12 16 20+ 05					
6.	What is your current marital status?					
	Single Married / long term relationship					
	Divorced Widower					
	Other (please specify): (please					

PI -	I prefer to leave all decisions to my doctor. or Delegate Signature Date and Time
	I prefer that my doctor make the final decision after seriously considering my opinior
	I prefer to make the final decision after seriously considering my doctor's opinion I prefer that we share responsibility for deciding.
	I prefer to make the final decision myself.
11.	. Pick one of the following statements which best describes how you prefer to make decisions about prostate cancer screening.
	No
10.	. Have you ever had a prostate biopsy? Yes
	No Never had a PSA
	Yes
€.	Do you know your most recent PSA test result?
	Yes No
3.	Have you ever heard of a PSA, or prostate specific antigen test?
	No I don't know
	Yes - some other relative
	Yes - my father, brother, or son

AIM 3 - EVALUATION: PRE-TEST QUESTIONNAIRE

Study ID:					
Here are some questions about prostate cancer. Please check (\checkmark) an answer next to each question. If you are not sure of the answer to a question, check "Not sure."					
		Yes	No	Not Sure	
1.	Will some men never know they have prostate cancer?	[]	[]	[]	
2.	Is a PSA test a blood test for prostate cancer?	[]	[]	[]	
3.	Is urinary incontinence a side effect of treatment for processor.	state []	[]	[]	
4.	Do women have prostates?	[]	[]	[]	
5.	Can a man get a woman pregnant after surgery for prosta cancer?	ate []	[]	[]	
6.	Is brachytherapy a kind of treatment for prostate cancer?	[]	[]	[]	
7.	When found at an early stage, is prostate cancer almost always curable?	[]	[]	[]	
8.	As a man gets older, does his risk of prostate cancer go u	ıp? []	[]	[]	
9.	Is impotence a side effect of treatment for prostate cancer	er? []	[]	[]	
10.	Are African American men at less risk of prostate cancel other men?	r than	[]	[]	
11.	Is Benign Prostatic Hyperplasia (BPH) a kind of prostate cancer?	[]	[]	[]	
12.	Is a biopsy necessary to determine if a man has prostate cancer?	[]	[]	[]	
13.	Will a patient die of prostate cancer if it has spread to of parts of the body?	her []	[]	[]	
14.	Do men with prostate cancer in their families have a high chance of getting prostate cancer?	her []	[]	[]	
15.	Does a high PSA level mean a man has prostate cancer?	[]	[]	[]	
16.	Is surgery the only treatment for prostate cancer?	[]	[]	[]	
17.	Are men with an enlarged prostate more likely to get car	ncer? []	[]	[]	
PI	PI or Delegate Signature Date and Time				
PI	or Delegate Printed Name	PI or Delegate I	Employee	ID#	

AIM 3 - EVALUATION: POST-TEST QUESTIONNAIRE

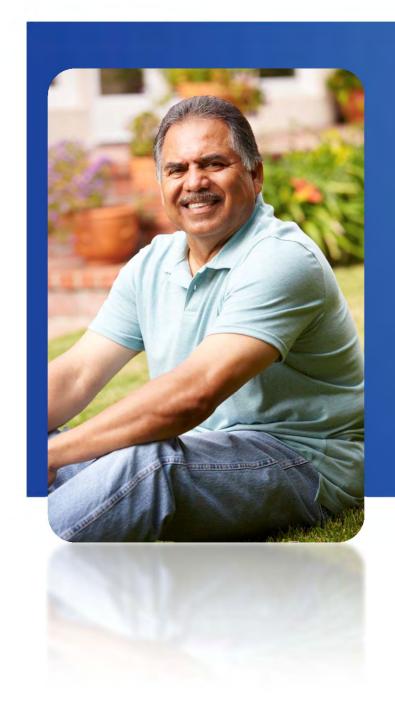
Stı	udy ID:
	ere are some questions on what you thought about the slide set. Please check (\checkmark) an answer xt to each question.
1.	How would you rate the amount of information given in the slide set decision aid?
	 [] Much less than wanted [] Little less than wanted [] About right [] Little more than wanted [] Much more than wanted
2.	How would you rate the length of the slide set decision aid?
	 [] Much too long [] Little too long [] About right [] Should have been a little longer [] Should have been much longer
3.	How clearly were the issues presented in the slide set decision aid?
	[] Everything clear[] Most things clear[] Some things unclear[] Most things unclear
4.	How would you rate the presentation?
	 [] Clearly slanted to screening [] Slightly slanted to favor screening [] Completely balanced [] Slightly slanted to favor not screening [] Clearly slanted to favor not screening

5.	Would you recommend this slide set decision aid to other people facing this decision?
	[] Yes [] No [] Unsure
6.	Was the slide set decision aid you viewed interesting?
	[] Yes [] No [] Unsure
7.	Did the slide set decision aid you viewed help you understand prostate cancer screening?
	[] Yes [] No [] Unsure
8.	Did the slide set decision aid you viewed give you information that was useful?
	[] Yes [] No [] Unsure
9.	Would you like to view the slide set decision aid again?
	[] Yes [] No [] Unsure
10.	Does the slide set decision aid use language that you understand?
	[] Yes [] No [] Unsure

11.	Would you like to ask questions about what you viewed?				
	[] Yes [] No [] Unsure				
	Would you like to have the opportunity to ask questions while you set decision aid?	ou are goi	ng over t	he slide	
	[] Yes [] No [] Unsure				
13.	Did you feel the decision aid related to you and persons like you	?			
	[] Yes [] No [] Unsure				
14.	Would you like decision aids similar to this one for other health	care decis	ions you	face?	
	[] Yes [] No [] Unsure				
	Here are some questions about prostate cancer. Please check (\checkmark) an answer next to each question. If you are not sure of the answer to a question, check "Not sure."				
		Yes	No	Not Sure	
1.	Will some men never know they have prostate cancer?	[]	[]	[]	
2.	Is a PSA test a blood test for prostate cancer?	[]	[]	[]	
3.	Is urinary incontinence a side effect of treatment for prostate cancer?	[]	[]	[]	
4.	Do women have prostates?	[]	[]	[]	
5.	Can a man get a woman pregnant after surgery for prostate cancer?	[]	[]	[]	
6.	Is brachytherapy a kind of treatment for prostate cancer?	[]	[]	[]	

		Yes	No	Not Sure
7.	When found at an early stage, is prostate cancer almost always curable?	[]	[]	[]
8.	As a man gets older, does his risk of prostate cancer go up?	[]	[]	[]
9.	Is impotence a side effect of treatment for prostate cancer?	[]	[]	[]
10.	Are African American men at less risk of prostate cancer than other men?	[]	[]	[]
11.	Is Benign Prostatic Hyperplasia (BPH) a kind of prostate cancer?	[]	[]	[]
12.	Is a biopsy necessary to determine if a man has prostate cancer?	[]	[]	[]
13.	Will a patient die of prostate cancer if it has spread to other parts of the body?	[]	[]	[]
14.	Do men with prostate cancer in their families have a higher chance of getting prostate cancer?	[]	[]	[]
15.	Does a high PSA level mean a man has prostate cancer?	[]	[]	[]
16.	Is surgery the only treatment for prostate cancer?	[]	[]	[]
17.	Are men with an enlarged prostate more likely to get cancer?	[]	[]	[]

PI or Delegate Signature	Date and Time
PI or Delegate Printed Name	PI or Delegate Employee ID#

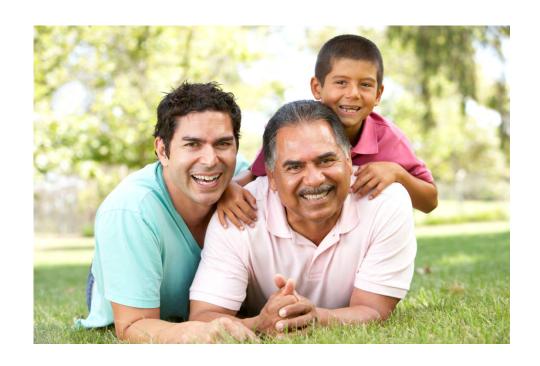


Pruebas de detección del cáncer de próstata

¿Debería hacerme las pruebas? La decisión es mía.

PARA QUE CUMPLAS MUCHOS MÁS"





El cáncer de próstata afecta a muchos hombres. Existen pruebas para detectarlo temprano.

Esta información le ayudará a decidir si usted quiere hacerse estas pruebas.

¿Son las pruebas de detección la mejor opción para mí?

Puede haber tanto beneficios como riesgos con las pruebas de detección y el tratamiento para cáncer de próstata.

Las investigaciones aún no han demostrado que los beneficios son mayores que los riesgos.

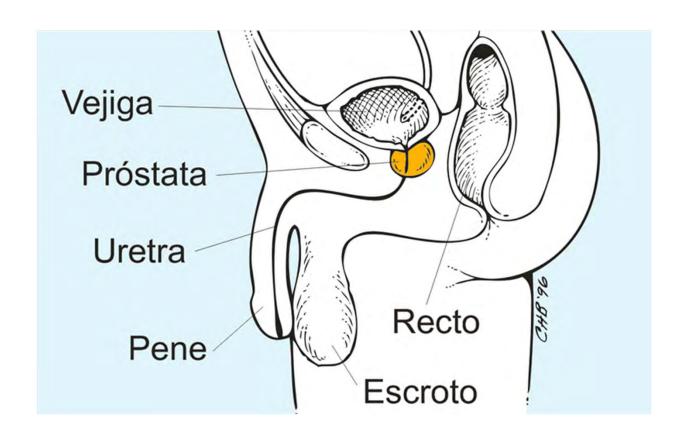
¿Qué debo hacer si tengo síntomas de la próstata?

Esta información es para hombres que no tienen síntomas de la próstata.

Hable con un médico inmediatamente si tiene:

- problemas al orinar
- sangre en la orina
- dolor al orinar

¿Qué es la próstata?



¿Qué es el cáncer de próstata?

Comienza en su cuerpo cuando células normales empiezan a crecer sin control.

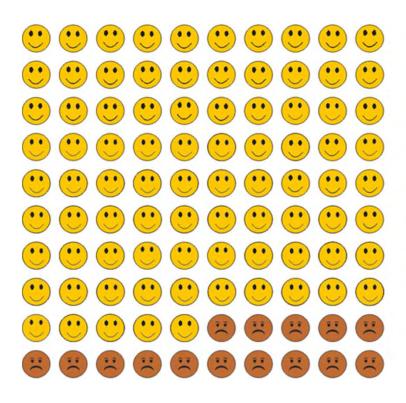
- En el cáncer de próstata, las células de la próstata crecen sin control.
- Las células de cáncer pueden:
 - propagarse y afectar órganos cercanos
 - propagarse a partes distantes del cuerpo y causar problemas

¿Son iguales todos los casos de cáncer de próstata?

- No. Unos cánceres crecen lentamente:
 - Si no son tratados, pueden no causar problemas por muchos años.
- Otros son más agresivos y crecen rápidamente. Éstos pueden:
 - propagarse a otras partes del cuerpo
 - causar dolor intenso
 - causar otros problemas
 - causar la muerte

¿Cuál es mi probabilidad de desarrollar cáncer de próstata?

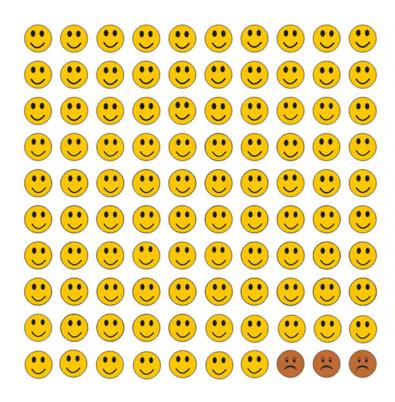
15 de cada 100 (15%) hombres hispanos serán diagnosticados con cáncer de próstata en su vida.



- = hombre no diagnosticado con cáncer de próstata
- = hombre diagnosticado con cáncer de próstata

¿Cuál es mi probabilidad de morir de cáncer de próstata?

3 de cada 100 (3%) hombres hispanos morirán debido al cáncer de próstata.



- = hombre que no muere de cáncer de próstata
- = hombre que muere de cáncer de próstata



- El examen PSA (por sus siglas en inglés)
 - También se conoce como APE, que significa
 Antígeno Prostático Específico.
- El examen rectal, DRE (por sus siglas en inglés)
 - También se conoce como el examen rectal digital o examen rectal.

¿Qué es la prueba PSA?

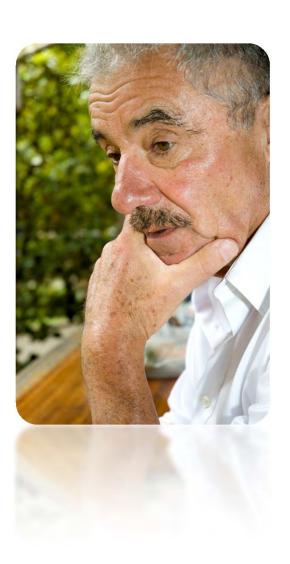
- El antígeno prostático específico es una proteína producida por la glándula prostática.
- La prueba PSA mide la cantidad de esta proteína en su sangre.
- Se hace tomando una pequeña cantidad de sangre de una vena de su brazo.





- Es un examen físico que puede indicar si el tamaño, la forma y la textura de la próstata son normales.
- El médico coloca un dedo, cubierto con un guante lubricado, en su recto para palpar la glándula prostática.
- Puede ayudar a detectar anormalidades o cáncer que la prueba PSA no detectaría.

¿Pueden las pruebas de detección decirme con seguridad que no tengo cáncer de próstata?



No.

No existe una prueba perfecta para detectar el cáncer de próstata.

¿Pueden las pruebas de detección decirme con seguridad que no tengo cáncer de próstata?

El examen rectal

- Si no sugiere cáncer, aun así puede tener cáncer.
- No puede detectar la mayoría de los cánceres.
- Puede detectar el cáncer aun cuando los niveles de PSA no sugieran cáncer.

La prueba PSA

- No existe un nivel de PSA que diga con seguridad que el cáncer de próstata está o no presente.
- Los niveles de PSA pueden ser bajos cuando el cáncer está presente.



La prueba PSA

- Sus probabilidades de tener cáncer de próstata aumentan a medida que su nivel de PSA aumenta.
- Los niveles de PSA pueden estar alto cuando hay cáncer, infecciones y otros problemas de la próstata.
- Tener un nivel alto de PSA NO siempre significa que usted tiene cáncer de próstata.

Si su nivel de PSA es alto, necesitará hacerse otras pruebas para saber la causa.

¿Cómo saber si tengo cáncer de próstata?

Si su nivel de PSA o su examen rectal sugieren cáncer, es posible que puede necesitar una **biopsia** - un examen para *diagnosticar* cáncer.



Una biopsia no es una prueba de detección.

¿Qué es una biopsia?

El médico:

- introduce una sonda ultrasónica en el recto
- utiliza la sonda para guiar una aguja
- extrae muestras de la glándula prostática

Estas muestras se observan en el microscopio.

Se hace en una consulta y toma una hora.



¿Cuáles son los riesgos de la biopsia?

Hay algunos riesgos y efectos secundarios que pueden ocurrir con una biopsia.

- Poco riesgo:
 - sangramiento del recto
 - infección
- Común:
 - sangre en la orina (se resuelva con tratamiento)

¿Basado en mi nivel de PSA, cuál es mi probabilidad de tener cáncer de próstata?

Si el nivel de PSA es de 4 o más alto:

La biopsia detectará el cáncer de próstata en 30 de cada 100 (30%) hombres.

- = hombres a quienes
 no se les detecta
 cáncer de próstata
 en una biopsia
- = hombres a quienes
 sí se les detecta
 cáncer de próstata
 en una biopsia

¿Basado en mi nivel de PSA, cuál es mi probabilidad de tener cáncer de próstata?

Si el nivel de PSA es menor de 4:

La a biopsia detectará el cáncer de próstata en 15 de cada 100 (15%) hombres.

- = hombres a quienes
 no se les detecta
 cáncer de próstata
 en una biopsia
- = hombres a quienes
 sí se les detecta
 cáncer de próstata
 en una biopsia

¿Qué pasa si me hago las pruebas de detección de cáncer de próstata?

Le hacen una prueba PSA y tal vez un examen rectal. Si los resultados son preocupantes, se le hace una biopsia.

- Posibles beneficios:
 - detectar cáncer de próstata en una etapa temprana
 - mejor probabilidad de ser tratado y curado
 - prevenir dolor y sufrimiento
 - dar tranquilidad

¿Qué pasa si me hago las pruebas de detección de cáncer de próstata?

- Posibles riesgos:
 - Su nivel de PSA puede ser bajo, aun si hay cáncer.
 - Puede preocuparse por los resultados.
 - Puede detectar un cáncer que tal vez nunca le hubiera causado problemas.
 - Puede resultar en tratamiento y los efectos secundarios del tratamiento:
 - problemas para controlar la orina, problemas con los intestinos, y problemas sexuales

¿Qué pasa si <u>no me hago</u> las pruebas de detección de cáncer de próstata?

Le hacen sus chequeos médicos regulares. Puede cambiar de opinión y hacerse las pruebas en el futuro.

- Posibles beneficios:
 - Evita la preocupación que podría sentir a causa de las pruebas.
 - Evita recibir tratamiento para un cáncer que quizá nunca le hubiera causado problemas.
 - Evita los efectos secundarios que se pueden presentar con el tratamiento.

¿Qué pasa si <u>no me hago</u> las pruebas de detección de cáncer de próstata?

- Posibles riesgos:
 - tener un cáncer de próstata en una etapa temprana y no saberlo
 - tener un cáncer de próstata que más adelante le causará síntomas o acortará su vida, y pudiera no tener oportunidad de encontrarlo a tiempo

¿Cómo decido si las pruebas de detección son la mejor opción para mí?

Evalúe sus opciones y decida lo que es importante para usted.

- La decisión es suya.
- En esta área, el médico no es el único experto.



¿Qué es más importante para usted?

Razones por las que un hombre puede decidir a <u>hacerse</u> las pruebas:	Razones por las que un hombre puede decidir a <u>no</u> <u>hacerse</u> las pruebas:
Estaré tranquilo cuando sepa los resultados de las pruebas.	Me voy a preocupar acerca de los resultados de las pruebas.
Sabré si tengo cáncer de próstata o no.	Pudiera encontrar un cáncer de próstata que tal vez nunca me cause problemas ni acorte mi vida.
Tengo una mejor oportunidad de obtener un tratamiento para el cáncer si se detecta tempranamente.	Si se detecta cáncer tal vez tendría que lidiar con el tratamiento y los efectos secundarios.



Puede desear hacerse las pruebas si:

- Valora el detectar el cáncer tempranamente
- Está dispuesto a ser tratado sin tener un beneficio asegurado
- Está dispuesto a correr el riesgo de un daño urinario,
 sexual o intestinal causado por el tratamiento de cáncer de próstata, como cirugía y radiación

Puede desear no hacerse las pruebas si:

- Le da más valor a evitar los riesgos causados por las pruebas y el tratamiento, como preocupaciones o problemas urinarios, sexuales e intestinales
- Está dispuesto a aceptar la posibilidad de que pudiera tener una forma de cáncer de próstata agresiva y no saberlo antes de que le cause algún daño

La decisión es suya.

¿Qué recomienda la Sociedad Americana Contra el Cáncer?

Recomienda que todos los hombres tomen una decisión informada acerca de las pruebas de detección.

- A partir de los 50:
 - Hable con su médico acerca de las pruebas para detectar el cáncer de próstata y su tratamiento.
 - Debe evaluar los riesgos y los posibles beneficios.
 - Piense en lo que es importante para usted.
 - Luego debería decidir si hacerse las pruebas es la mejor opción para usted.

¿Qué recomienda la Sociedad Americana Contra el Cáncer?

Si usted:	Comience este diálogo con su médico:
Es de raza negra o tiene un padre o hermano que haya padecido cáncer de próstata antes de los 65 años	Desde los 45 años
Tiene 2 o más parientes cercanos que hayan padecido de cáncer de próstata a una edad temprana	Desde los 40 años

- Si decide hacerse las pruebas, debe tomar la prueba de sangre PSA con o sin examen rectal.
- La frecuencia de las pruebas dependerá de su nivel de PSA.

¿Ahora qué debo hacer?

- Hable con su médico.
- Piense en lo que es importante para usted.
- Decida qué es lo mejor para usted y su familia.



¿Dónde puedo conseguir más información?

- La Sociedad Americana Contra el Cáncer
 - **1-800-227-2345**
 - http://www.cancer.org/Espanol/cancer/Cancerde
 prostata/index
- Los Centros para el Control y la Prevención de Enfermedades
 - http://www.cdc.gov/spanish/cancer/prostate/
- Mayo Clinic
 - http://www.mayoclinic.org/espanol/enfermedad
 es-y-tratamientos/cancer-de-prostata



PARA QUE CUMPLAS MUCHOS MÁS~





Slide 2



El cáncer de próstata afecta a muchos hombres. Existen pruebas para detectarlo temprano.

Esta información le ayudará a decidir si usted quiere hacerse estas pruebas.

Slide 3

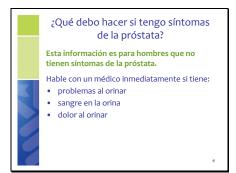


Puede haber tanto beneficios como riesgos con las pruebas de detección y el tratamiento para cáncer de próstata. Las investigaciones aún no han demostrado que los beneficios son mayores que los riesgos.

Aquí hablaremos más sobre el cáncer de próstata y los posibles beneficios y riesgos de las pruebas de detección y del tratamiento. Después de ver esta presentación, esperamos que usted pueda decidir si quiere hacerse o no las pruebas de detección. Si tiene otras preguntas después de ver esta

presentación, por favor hable con su médico o consejero médico.

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La información de esta presentación es para ayudar a hombres que no tienen síntomas de la próstata a decidir si quieren hacerse las pruebas de detección. Hable con un médico inmediatamente si tiene: problemas al orinar, sangre en la orina, o dolor al orinar.

Estos síntomas a menudo son causa de otros problemas de la próstata, pero también pueden ser causados por el cáncer de próstata. La única manera de saber lo que está mal es consultar un médico.

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La próstata es una glándula que se encuentra sólo en los hombres. Es parte del sistema reproductivo y ayuda a producir semen. Se encuentra delante del recto y debajo de la vejiga. Una próstata saludable es el tamaño de una pequeña lima.



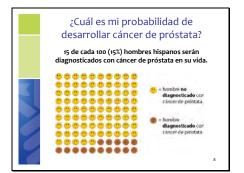
El cáncer comienza en su cuerpo cuando células normales empiezan a crecer sin control. En el cáncer de próstata, las células de la próstata crecen sin control. Las células de cáncer se pueden propagar y afectar órganos cercanos. También se pueden propagar a partes distantes del cuerpo y causar problemas.

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El cáncer de próstata puede causar la muerte, pero no todos los casos de cáncer de próstata son iguales. Muchos casos de cáncer de próstata crecen lentamente. Por lo general, si no son tratados, estos cánceres pueden no causar problemas por muchos años.

Algunos casos de cáncer de próstata son más agresivos y crecen rápidamente. Éstos pueden propagarse a otras partes del cuerpo, donde pueden causar dolor intenso y otros problemas, e incluso pueden causar la muerte.



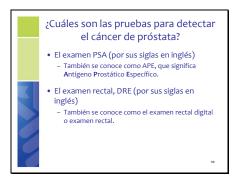
Quince de cada cien hombres hispanos serán diagnosticados con cáncer de próstata en su vida,

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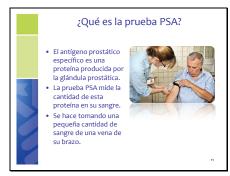


y tres de cada 100 hombres hispanos morirán debido al cáncer de próstata.

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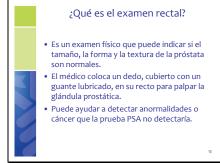


Un examen de sangre PSA y un examen rectal pueden indicarle a su médico el estado de su próstata. El examen PSA (por sus siglas en inglés) también se conoce como APE. APE significa Antígeno Prostático Específico en español. El examen rectal, DRE (por sus siglas en inglés) también se conoce como el examen rectal digital o examen rectal.



El antígeno prostático específico es una proteína producida por la glándula prostática. La prueba PSA mide la cantidad de esta proteína en su sangre. Se hace tomando una pequeña cantidad de sangre de una vena de su brazo.

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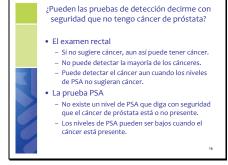
El examen rectal es un examen físico que puede indicar si el tamaño, la forma y la textura de la próstata son normales. El médico coloca un dedo, cubierto con un guante lubricado, en su recto para palpar la glándula prostática.

Si decide hacerse las pruebas de detección del cáncer de próstata, puede elegir hacerse solo la prueba del PSA o también el examen rectal. Para algunas personas, el examen rectal es penoso o desagradable. Sin embargo, puede ayudar a detectar anormalidades o cáncer que la prueba PSA no detectaría.



Las pruebas de detección no pueden decirle con seguridad que no tiene cáncer de próstata. En otras palabras, no existe una prueba perfecta para detectar el cáncer de próstata.

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El examen rectal no es perfecto. Si su examen rectal no sugiere cáncer, aun así usted puede tener cáncer de próstata. La mayoría de los cánceres no pueden detectarse con un examen rectal. Pero algunas veces los exámenes rectales pueden detectar el cáncer aun cuando los niveles de PSA no sugieran cáncer.

La prueba PSA no es perfecta. No existe un nivel de PSA que diga con seguridad que el cáncer de próstata está o no presente. Los niveles de PSA pueden ser bajos cuando el cáncer está presente.

¿Pueden las pruebas de detección decirme con seguridad que no tengo cáncer de próstata?

• La prueba PSA

- Sus probabilidades de tener cáncer de próstata aumentan a medida que su nivel de PSA aumenta.

- Los niveles de PSA pueden estar alto cuando hay cáncer, infecciones y otros problemas de la próstata.

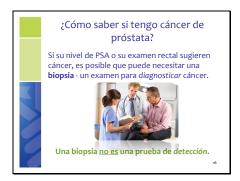
- Tener un nivel alto de PSA NO siempre significa que usted tiene cáncer de próstata.

Si su nivel de PSA es alto, necesitará hacerse otras pruebas para saber la causa.

Sus probabilidades de tener cáncer de próstata aumentan a medida que su nivel de PSA aumenta.

Los niveles de PSA pueden estar altos cuando hay cáncer de próstata y también cuando hay infecciones de la próstata y otros problemas de la próstata. Por lo que, tener un nivel alto de PSA NO siempre significa que usted tiene cáncer de próstata. Si su nivel de PSA es alto, usted necesitará hacerse otras pruebas para saber la causa.

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Si su nivel de PSA o su examen rectal sugieren la presencia de cáncer, es posible que usted puede necesitar una **biopsia** de su glándula prostática.

Una biopsia es un examen para diagnosticar cáncer de la próstata. Una biopsia no es una prueba de detección.

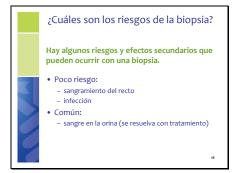
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En una biopsia el médico introduce una sonda ultrasónica en el recto. El médico utiliza la sonda para guiar una aguja.

El médico extrae varias muestras de la glándula prostática. Estas muestras se observan en el microscopio para detectar células cancerosas.

La biopsia se hace en una consulta y solamente toma alrededor de una hora.



Hay algunos riesgos y efectos secundarios que pueden ocurrir con una biopsia. Hay poco riesgo de sangramiento del recto y poco riesgo de infección. Sangre en la orina es común y se resuelva con tratamiento.

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La biopsia detectará el cáncer de próstata en 30 de cada 100 hombres con nivel de PSA de 4 o más.

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y detectará el cáncer de próstata en 15 de cada 100 hombres con nivel de PSA menor de 4.

¿Qué pasa si me hago las pruebas de detección de cáncer de próstata?

Le hacen una prueba PSA y tal vez un examen rectal. Si los resultados son preocupantes, se le hace una biopsia.

• Posibles beneficios:

- detectar cáncer de próstata en una etapa temprana

- mejor probabilidad de ser tratado y curado

- prevenir dolor y sufrimiento

- dar tranquilidad

Si decide hacerse las pruebas de detección de cáncer de próstata, a usted le hacen una prueba PSA y tal vez un examen rectal. Si los resultados de sus pruebas son preocupantes, a usted se le hace una biopsia.

Posibles beneficios si se hace las pruebas son que las pruebas de detección pueden detectar cáncer de próstata en una etapa temprana – mientras es pequeño y antes de que se propague; si se detecta en una etapa temprana, hay una mejor probabilidad de ser tratado y curado; puede prevenir el dolor y el sufrimiento causados por el cáncer; y el hacerse las pruebas le puede dar tranquilidad.

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¿Qué pasa si me hago las pruebas de detección de cáncer de próstata?

• Posibles riesgos:

- Su nivel de PSA puede ser bajo, aun si hay cáncer.

- Puede preocuparse por los resultados.

- Puede detectar un cáncer que tal vez nunca le hubiera causado problemas.

- Puede resultar en tratamiento y los efectos secundarios del tratamiento:

• problemas para controlar la orina, problemas con los intestinos, y problemas sexuales

Posibles riesgos si se hace las pruebas son que su nivel de PSA puede ser bajo, aun si hay cáncer presente; usted puede preocuparse por los resultados; hacerse las pruebas puede detectar un cáncer que tal vez nunca le hubiera causado problemas; y hacerse las pruebas puede resultar en tratamiento y los efectos secundarios del tratamiento - estos incluyen problemas para controlar la orina, problemas con los intestinos, y problemas sexuales.

¿Qué pasa si no me hago las pruebas de detección de cáncer de próstata?

Le hacen sus chequeos médicos regulares. Puede cambiar de opinión y hacerse las pruebas en el futuro.

- Posibles beneficios:
 - Evita la preocupación que podría sentir a causa de las pruebas.
 - Evita recibir tratamiento para un cáncer que quizá nunca le hubiera causado problemas.
 - Evita los efectos secundarios que se pueden presentar con el tratamiento.

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Si decide no hacerse las pruebas de detección de cáncer de próstata, a usted le hacen sus chequeos médicos regulares pero no las pruebas de detección de cáncer de próstata. Usted puede cambiar de opinión y hacerse las pruebas en el futuro.

Posibles beneficios si no se hace las pruebas son que evita la preocupación que podría sentir a causa de las pruebas, evita recibir tratamiento para un cáncer que quizá nunca le hubiera causado problemas, y evita los efectos secundarios que se pueden presentar con el tratamiento.

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¿Qué pasa si no me hago las pruebas de detección de cáncer de próstata?

- Posibles riesgos:
- tener un cáncer de próstata en una etapa temprana y no saberlo
- tener un cáncer de próstata que más adelante le causará síntomas o acortará su vida, y pudiera no tener oportunidad de encontrarlo a tiempo

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Posibles riesgos si no se hace las pruebas son que usted pudiera tener un cáncer de próstata en una etapa temprana y no saberlo; y usted pudiera tener un cáncer de próstata que más adelante le causará síntomas o acortará su vida, y pudiera no tener oportunidad de encontrarlo a tiempo.

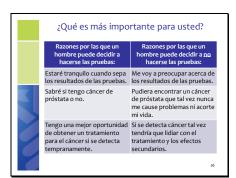


Para decidir si las pruebas de detección son la mejor opción para usted, evalúe sus opciones y decida lo que es importante para usted.

La decisión es suya. En esta área, el médico no es el único experto.

Conozca los hechos y usted podrá decidir si hacerse las pruebas es importante para usted.

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Hay muchas razones por las que los hombres deciden hacerse o no las pruebas de detección de cáncer de próstata. Algunas razones están enlistadas aquí. Reflexione en cuáles de estas razones son importantes para usted. Si piensa:

- Estaré tranquilo cuando sepa los resultados de las pruebas.
- Sabré si tengo cáncer de próstata o no.
- Tengo una mejor oportunidad de obtener un tratamiento para el cáncer si se detecta tempranamente.

Quizá decide a hacerse las pruebas. Si piensa:

- Me voy a preocupar acerca de los resultados de las pruebas.
- Pudiera encontrar un cáncer de próstata que tal vez nunca me cause problemas ni acorte mi vida
- Si se detecta cáncer tal vez tendría que lidiar con el tratamiento y los efectos secundarios.

Quizá decide a no hacerse las pruebas.



Esta es otra manera para ayudarle decidir. Usted puede desear hacerse las pruebas si:

- Usted valora el detectar el cáncer tempranamente
- Usted está dispuesto a ser tratado aun sin tener un beneficio asegurado
- Usted está dispuesto a correr el riesgo de un daño urinario, sexual o intestinal causado por el tratamiento de cáncer de próstata, tales como cirugía y radiación.

Usted puede desear <u>no hacerse</u> las pruebas si:

- Usted le da más valor a evitar los riesgos causados por las pruebas y el tratamiento, tales como preocupaciones o problemas urinarios, sexuales e intestinales
- Usted está dispuesto a aceptar la posibilidad de que pudiera tener una forma de cáncer de próstata agresiva y no saberlo antes de que le cause algún daño
 La decisión es suya.

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La Sociedad Americana Contra el Cáncer recomienda que todos los hombres tomen una decisión informada acerca de las pruebas de detección.

A partir de los 50 años de edad, hable con su médico o consejero médico acerca de las pruebas para detectar el cáncer de próstata y su tratamiento. Usted debe evaluar los riesgos y los posibles beneficios. Piense en lo que es importante para usted. Luego debería decidir si hacerse las pruebas es la mejor opción para usted.



Si usted es de raza negra o tiene un padre o hermano que haya padecido cáncer de próstata antes de los 65 años, comience este diálogo con su médico desde los 45 años. Los hombres con 2 o más parientes cercanos que hayan padecido de cáncer de próstata a una edad temprana deberían comenzar esta plática al cumplir los 40 años.

Si usted decide hacerse las pruebas, debe tomar la prueba de sangre PSA con o sin examen rectal. La frecuencia de las pruebas dependerá de su nivel de PSA.



Por fin:

- Hable con su médico acerca de las pruebas de detección.
- Piense en lo que es importante para usted, y
- Decida qué es lo mejor para usted y su familia.

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Aquí hay enlaces de la Sociedad Americana Contra el Cáncer, los Centros para el Control y la Prevención de Enfermedades, y Mayo Clinic donde puede conseguir información en español.

Para mayor información sobre cáncer, preguntas, y apoyo, llame a La Sociedad Americana Contra el Cáncer las 24 horas del día, los 7 días de la semana al 1-800-227-2345.

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¿Preguntas?

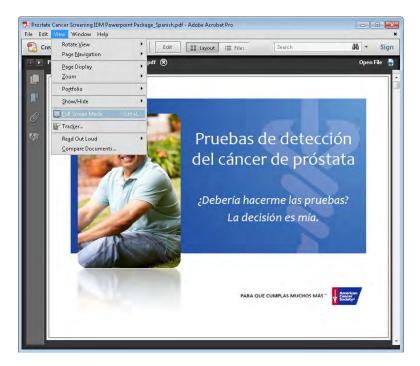
Cómo usar este paquete PDF

Este paquete PDF contiene tres archivos PDF individuales:

- Diapositivas de una presentación acerca de cáncer de próstata
- Un archivo que contiene las mismas diapositivas, junto con notas para el presentador.
- Esta hoja de instrucciones.

Diapositivas

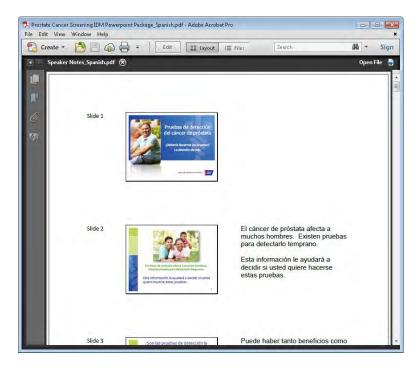
Este PDF contiene las diapositivas que mostrará a su audiencia durante su presentación. Para hacerlas aparecer en modo de pantalla completa, seleccione "Full Screen Mode" en el menú "View" (véase abajo). Las diapositivas entonces aparecerán así como una presentación "PowerPoint." Puede mover de una diapositiva a la siguiente con las flechas en su teclado o el botón rueda en su ratón. Para salir del modo pantalla completa, pulse la tecla "ESC" en su teclado.



Notas

Este PDF contiene las notas de presentador que debe usar durante la presentación. No son para enseñar a la audiencia, pero usted puede imprimirlas y referirse a ellas mientras habla.

Si usted desea mas información acerca de este tema, puede acceder la guía detallada sobre cáncer de próstata en www.cancer.org. También considere consultar los recursos mencionados en la penúltima diapositiva.



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